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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1989

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

H.R. 4783

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 1989, AND FOR OTHER PURPOSES

Part 4 (Pages 1-861)

Nondepartmental witnesses

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1989

THURSDAY, MAY 26, 1988

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:45 a.m., in room SD-138, Dirksen Senate Office Building, Hon. Lawton Chiles (chairman) presiding.

Present: Senators Chiles, Inouye, and Weicker.

NONDEPARTMENTAL WITNESSES

Senator CHILES. This morning the subcommittee will continue with the sixth of 9 days of hearings with public witnesses, with testimony focusing on the programs funded by the subcommittee and the 14 related agencies.

During these several sessions, the subcommittee is going to hear testimony from approximately 225 witnesses, the highest number yet to be heard by the subcommittee in a single year. Because of that large number of witnesses, we request that each witness keep their oral testimony brief. You should be assured that your full statement will be included in the printed record.

In order to help us stay on schedule, we are trying to use this green-red light system. When the red light goes on, your time has expired, and we will need to ask you to conclude your remarks so that each witness will have a fair opportunity to be heard.

STATEMENT OF MELVIN L. RUBIN, M.D., CHAIRMAN, DEPARTMENT OF OPHTHALMOLOGY, UNIVERSITY OF FLORIDA, ON BEHALF OF RESEARCH TO PREVENT BLINDNESS

Senator CHILES. Our first witness this morning will be Dr. Melvin L. Rubin representing Research to Prevent Blindness.

Dr. Rubin is from the University of Florida, director of the Eye Institute.

Dr. Rubin?

Dr. RUBIN. Thank you, Senator.

My name is Melvin Rubin. I am chairman of the Department of Ophthalmology at the University of Florida, and past president of the American Board of Ophthalmology, and current President of the American Academy of Ophthalmology.

I am here basically to represent the Research to Prevent Blindness and the Citizens Committee Budget for fiscal year 1989 for the National Eye Institute, and I am here to urge a budget request of $393 million for eye research.

I don't think I have to express the importance of blindness. There are probably 14 million people who have some impaired vision in the United States, and over 1 million are legally blind.

Now, we sometimes pass this off, but all you have to know yourselves is when you have smudged eyeglasses or a dirty windshield, you realize what kind of an impact it is. And you can personally experience that.

In general, the level of blindness in the United States costs the Government $16 billion every year. Any impact that we can make to reduce that would be a major contribution to saving funds.

What I would like to do is emphasize that the impact on reducing blindness is ongoing. We have many projects every year from research that the Eye Institute has sponsored, just even last month dealing with premature children, the impact of treating, a sample treatment to improve the level of vision impairment by 50 percent. The project cost $4.5 million, and the estimated annual savings are $100 million a year.

You get a tremendous amount of bang for your buck in investing in trying to prevent blindness. There is a diabetic retinopathy study that would be NEI sponsored. It costs only $10 million. It's estimated savings are half a billion dollars a year.

Age-related macular degeneration, treatment with krypton lasers, all of these studies are ongoing and have been completed and sponsored by the National Eye Institute. Even now, at the University of Florida we are studying different mechanisms for treating glaucoma and conducting glaucoma research.

Basic research is the important part, and basic research is—I understand the light is on. I will try to speed through. I just want to mention a couple of points. That is, an ounce of prevention is worth a ton of cure. If you can prevent even a few hundred patients from becoming blind, the impact dollarwise is absolutely astronomical.

I would like to encourage through many research programs, I would like to encourage the reinstitution of at least $10 million for construction of research space. A very large study has been accomplished by RPB in analyzing the space needs. Over 1 million square feet of space will be required over the next 7 or 8 years through studies of all the major teaching centers in the country, and we just are asking for an institution of $10 million for support.

This is seed money because at the University of Oregon, $1 million was awarded and was matched by $17 million of private and State funds for that support.

PREPARED STATEMENT

In summary, I emphasize that the support of eye research to the tune of $293 million is not just an appropriation, it is an investment with a tremendous leverage, and it saves the country a tremendous amount of money.

And I would like at this point to thank the committee for listening to my testimony.

[The statement follows:]

STATEMENT OF MELVIN L. RUBIN

My name is Dr. Melvin Rubin. I am President of the American Academy of Ophthalmology, Professor and Chairman of the Department of Ophthalmology and Director of the Eye Center at the University of Florida School of Medicine. It is a privilege to present the Citizens' Committee Budget for Fiscal Year 1989 under the auspices of Research to Prevent Blindness (RPB).

Vision is a precious gift indeed, the possible loss of which is an ever present fear from early childhood into our later years. A study of children here and in five other countries found that the possibility most haunting them, other than a parent's death, is that of going blind. RPB-sponsored Gallup Surveys conducted ten years apart show that the fear of blindness among American adults is second only to the fear of cancer. The unfortunate reality is that all of us are at risk. Fourteen million of our fellow Americans have serious visual impairment. Low-vision, the inability to read normal newspaper print even with eye glasses, afflicts 1.4 million citizens. Up to 900,000 are legally blind.

The cost of eye diseases and blindness is $16 billion a year. This staggering sum would be greater were it not for the wisdom and foresight of Congress in establishing the National Eye Institute (NEI) in 1968 with a mandate to develop and lead the nation's eye research program. In two decades we have made great leaps of progress in saving sight.

Through scientifically controlled clinical trials the NEI continues to demonstrate the results of Federally financed research as quickly as they are developed, assuring the safety and effectiveness of new therapies and making them available promptly to practicing ophthalmologists and their patients. It is imperative that sufficient funds be appropriated for continued intensive research and for the clinical trials which save this nation many times over the dollar amount invested.

Just last month NEI-funded scientists announced the first successful therapy for a devastating eye disorder in premature infants. Each year some 2,600 of these low-birthweight babies develop abnormal blood vessels in the eye that can lead to bleeding, scarring, retinal detachment and blindness. The scientists found that by freezing those vessels, the risk of visual loss can be reduced by half. The efficacy of the treatment was demonstrated in an NEI study that cost $9.6 million. The potential annual savings have been roughly estimated at well over $100 million in social services, medical care, and lost earnings.

NEI-sponsored studies have succeeded in reducing blindness by 60 percent in diabetics who experience the disastrous visual consequences of their disease. Clinical trials of newly-developed laser therapy of diabetic retinopathy cost $10.5 million and have resulted in an annual saving of $454 million. Subsequent trials to reduce vision loss at an earlier stage of diabetic retinopathy should save an additional $100 million annually. The cost of the trials was only $4 million.

Today tens of thousands of elderly citizens are being denied the rewards of retirement as a result of age-related eye problems that leave them severely disabled. The leading cause of blindness in those over 65 is macular degeneration -- a previously untreatable disorder that destroys central vision. The development of krypton laser therapy by NEI-supported scientists now makes it possible to delay or prevent the onset of blindness in 75 percent of those with one type of this insidious disease. The NEI clinical trials of this therapy cost $1.56 million. The potential annual saving is $57 million!

At the University of Florida, we are participating in a multi-center NEI-funded investigation to improve the success of treating advanced glaucoma. Glaucoma has been diagnosed in 1.5 million Americans and an equal number have the disease but don't know it. For thousands the disease is largely unmanageable. We are evaluating the benefits of injections of a substance called fluorouracil to reduce scar formation that often nullifies the effect of glaucoma surgery. Our research is providing primary data toward solution of this and other surgery-related problems. If we can reduce eye pressure in 30,000 patients each year through newly-developed laser therapy it will result in annual savings of $66 million.

Corneal and external eye diseases afflict 3.7 million Americans. They account for 10 million visits to physicians' offices each year and for one third of every dollar spent on eye care in the United States. The leading cause of corneal blindness is Herpes Simplex Virus (HSV) infection. NEI-supported scientists have uncovered a genetic flaw responsible for a several million-fold increase in the ability of the virus to spread to the central nervous system.

These studies are bringing us closer to the development of vaccines against both ocular and systemic Herpes infections. More than 32,000 citizens each year undergo corneal transplant surgery, while another 5,000 must wait, due to the shortage of donor tissue. Multi-center clinical trials of immunological matching of corneal tissue donors and recipients promise to substantially reduce the risk of rejection. Other research into proteins identified as growth factors may significantly speed the normal healing process in corneal and other diseases -- a major contribution to medicine and surgery.

The Citizens' Committee Budget before you recognizes our deep concern for the nationwide health problems posed by acquired immune deficiency syndrome (AIDS). AIDS patients have a 94 percent chance of developing potentially blinding retinal disease. An experimental drug, gancyclovir, has been shown to prevent or slow vision loss in these patients. Large-scale studies are planned to devise new forms of treatment for this and other AIDS-related eye diseases.

Obviously, research in the clinical treatment of eye disease is not enough. The explosion in advanced technology affords vast new opportunities to explore the cells, molecules and biochemistry involved in human sight, leading toward a deeper understanding of the basic causes of visual loss -- toward revolutionary new cures and preventives that will make many of today's therapies unnecessary.

Cataract, for instance, is present in six out of ten Americans over age 60. Thanks to the development of new surgical techniques and micro-instrumentation, more than one million cataract operations are performed annually in the U.S. at a cost of $2.5 billion for surgery and visual rehabilitation. Increased support of basic research into metabolic factors and photochemical processes is needed to significantly reduce the prevalence of this disease. If we could delay for ten years the formation of cataract in the aging there would be 450,000 fewer cataract operations each year and an annual saving of $607 million in direct costs alone.

Basic scientists supported by NEI grants recently identified the specific gene associated with retinoblastoma -- a blinding, life-threatening eye tumor in children -- achieving new ground not only in eye research but in far broader realms of medical science. This is the first human cancer gene to be isolated for any human cancer. The gene has now been cloned, making feasible a simple prenatal test for the disease. Early discovery and treatment can save the lives, as well as the eyes, of many of these children.

Mr. Chairman, we are at the edge of a new frontier in advanced biomedical technology. Exciting developments in NEI-sponsored research -- such as the promotion of new cell growth and the regeneration of neurons and successful restoration of nerve function in animals -- hold the promise that it may one day be possible to restore vision in patients who today are hopelessly blind. But the need for increased research funding, the shortage of trained research personnel, and the inadequacy of present laboratory space to accommodate the complex and sophisticated new technology, threaten to impede our progress.

I fervently hope that this Committee will recommend approval of the Citizens' proposed National Eye Institute budget for Fiscal Year 1989. Our request contemplates expenditures in the following categorical program areas: for Retinal and Choroidal Diseases, $119,672,000; for Corneal Diseases, $33,723,000; for Cataract, $21,514,000; for Glaucoma, $22,869,000; and for Strabismus, Amblyopia and Visual Processing, $55,017,000. We also recommend an appropriation of $30,755,000 for Intramural Research, Management and Program Services, for a total budget of $293,550,000.

In your determination of the total appropriation for the National Institutes of Health for Fiscal Year 1989, we most strongly urge the Congress to restore funds for the construction of eye research facilities through the National Eye Institute budget. Historically, the laboratory space needs of eye research have not been adequately addressed. During the 20-year life of the Health Research Facilities Construction Act, vision research received only a minuscule fraction of the $473 million made available for scientific laboratory construction purposes -- just a few hundred thousand dollars. No funds were expended under that law after 1969 and eight years later it became extinct. Not until the beginning of this decade were the highly specialized needs of vision research recognized. From 1980 through 1987 Congress appropriated $13.7 million for laboratory construction projects categorically associated with the National Eye Institute. The categorical appropriation approach, even at this rather meager level, provided a truly effective incentive for medical schools to seek matching funds from other sources, often greatly multiplying the effect of NEI financial support.

For example, in 1985 The Oregon Health Sciences University applied successfully to the National Eye Institute for a one million dollar matching construction grant. Then, with financial and fund raising campaign support from Research to Prevent Blindness (RPB), the University produced an additional $17 million in private and state funding to construct a vision center that will be a major international resource in ophthalmic science. Had it not been for those matching Federal construction funds it is unlikely that the project would have been undertaken.

I have here the results of a survey completed just last month to determine the current and future eye research space requirements of the nation's medical schools. The survey, conducted by Research to Prevent Blindness (RPB), reveals that more than 80 departments of ophthalmology at these institutions hope within the next seven years to more than double the amount of eye research space available to them, either through renovation or the construction of new facilities. Many of these eye departments are still locked into obsolescent quarters. Their physical capacity for eye research must be increased by an estimated one million square feet at a projected cost of $300 million if they are to keep pace with the rapid advance of technology and attract highly qualified scientists who will lead tomorrow's fight against blindness. We strongly recommended that Congress appropriate $10 million for eye research laboratory construction and renovation in the Fiscal Year 1989 budget of the National Eye Institute to help meet this urgent long-term need.

In summary, Mr. Chairman, our Citizens' Committee Budget is based upon a national research plan that results from the continuing evaluation and guidance of more than 350 leading scientists representing all areas of vision research. It is a realistic assessment of the resources needed to grasp existing opportunities for productive investigation. With judicious investment, we can reduce the tragedy of blindness and cost-effectively lessen the burden of health care on the people of the United States. I earnestly request that this Committee recommend approval of the Citizens' Budget of $293,550,000 for the National Eye Institute for Fiscal Year 1989. Proposed expenditures in all categories are specified in the Financial Tables appended to my statement.

NATIONAL EYE INSTITUTE FINANCING

BY ACTIVITY:	Fiscal Year 1988 Appropriation	Fiscal Year 1989 President's Budget Request	Fiscal Year 1989 Citizens' Budget
Grants:			
Research Grants............	$177,635,000	$181,075,000	$224,461,000
Extramural Research Laboratory Renovation, Construction and Instrumentation..........	--	0	10,000,000
Core and Specialized Center Grants............	7,346,000	7,346,000	12,100,000
Individual Training........	2,142,000	2,185,000	3,126,000
Institutional Training.....	3,478,000	3,548,000	4,608,000
Total Grants...........	190,601,000	194,154,000	254,295,000
Direct Operations:			
Intramural Laboratory and Clinical Research........	18,652,000	19,506,000	21,350,000
Research and Development Contracts................	7,506,000	7,006,000	8,500,000
Biometry, Epidemiology and Field Program........	1,200,000	1,250,000	1,650,000
Research Management and Program Services.....	6,988,000	7,105,000	7,755,000
Total Direct Operations............	34,346,000	34,867,000	39,255,000
TOTAL NEI OBLIGATIONS..	$224,947,000	$229,021,000	$293,550,000
BY PROGRAM:			
Extramural Research:			
Retinal and Choroidal Diseases.......	$ 95,731,000	$94,545,000	$119,672,000
Corneal Diseases...........	25,914,000	27,127,000	33,723,000
Cataract...................	16,241,000	16,837,000	21,514,000
Glaucoma...................	17,426,000	18,396,000	22,869,000
Strabismus, Amblyopia and Visual Processing........	42,795,000	44,255,000	55,017,000
Extramural Laboratory Renovation, Construction and Instrumentation......	--	--	10,000,000
Total Extramural Research..............	198,107,000	201,160,000	262,795,000

	Fiscal Year 1988 Appropriation	Fiscal Year 1989 President's Budget Request	Fiscal Year 1989 Citizens' Budget
Intramural Research:			
Laboratory and Clinical Research, Biometry and Epidemiology..............	19,852,000	20,756,000	23,000,000
Research Management and Program Services.....	6,988,000	7,105,000	7,755,000
Total Intramural Research..............	26,840,000	27,861,000	30,755,000
TOTAL NEI OBLIGATIONS..	$224,947,000	$229,021,000	$293,550,000

(RPB) SURVEY OF NATIONAL EYE RESEARCH SPACE REQUIREMENTS 1988 - 1995

NET SQUARE FOOTAGE AND FUNDS REQUIRED

		1988			1990			1992			1995		
Name of Institution	Existing Sq. Ft. Research	Under Negotiation Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Revovated	New	Estimated Cost
				$			$			$			$
U OF ALABAMA	4,000	-	47,450	9,200,000	-	-	110,000	500	-	57,500	1,000	8,000	1,080,000
ALBANY MED C	4,000	12,500	-	1,800,000	6,000	-	900,000	-	-	-	-	-	-
U OF ARIZONA	1,500	1,500	-	60,000	1,500	-	60,000	2,500	-	100,000	-	5,000	500,000
U OF ARKANSAS	4,630	3,000	12,000	1,350,000	-	-	-	-	-	-	12,000	24,000	4,320,000
BAYLOR C OF M	25,681	3,582	23,584	716,932	5,110	-	335,000	5,463	-0	300,465	800	-	52,500
BETHESDA EYE	5,950	-	-	-	-	30,000	8,000,000	-	45,000	12,000,000	-	30,000	8,000,000
BOSTON U	9,000	-	-	-	2,000	-	325,000	-	5,000	1,225,000	-	-	-
BROWN U													
U CALIF DAVIS	6,500	-	-	-	-	15,000	2,600,000	-	-	-	-	-	-
U CAL IRVINE													
U CALIF LA	65,000	500	67,000	22,600,000	2,000	-	400	5,000	-	1,000,000	7,000	-	1,400,000
U CALIF SD	3,700	-	18,000	5,500,000	-	3,500	700,000	-	-	-	-	-	-
U CALIF SF	15,000	-	-	-	11,000	26,000	13,600,000	-	-	-	-	-	-
U CAL SF FIP	15,500	2,500	-	250,000	10,000	10,000	4,000,000	4,500	5,000	1,925,000	4,000	-	600,000
U SO CALIF	27,000	-	-	-	-	36,000	18,000,000	23,000	-	5,000,000	42,000	-	5,600,000
CASE WESTERN	16,000	-	-	-	-	6,000	1,800,000	-	-	-	-	-	-
CHICAGO MED													
U OF CHICAGO	20,000	2,400	-	240,000	-	2,000	200,000	-	-	-	2,000	-	200,000
U CINCINNATI	2,000	150	-	65,000	1,000	-	100,000	2,500	-	250,000	4,000	-	400,000
U OF COLORADO	2,239	-	-	-	1,400	2,500	535,000	-	12,000	1,500,000	-	-	-
COLUMBIA U	25,500	-	-	-	15,000	-	1,125,000	12,000	-	1,000,000	6,500	-	1,000,000
U CONNECTICUT													
CORNELL	5,999	360	-	36,000	6,000	-	3,000,000	-	-	-	-	-	-
CREIGHTON U													
DARTMOUTH SM													
DUKE U	9,000	1,250	6,100	1,158,000	1,000	-	200,000	-	20,000	4,000,000	-	20,000	4,000,000
EINSTEIN COLL	4,000	2,200	-	330,000	1,000	-	150,000	-	-	-	-	20,000	4,000,000
EMORY U	65,000	100	-	5,000	5,000	-	13,000	5,000	-	20,000	5,000	-	20,000
ERI/RETINA FN	30,200	6,100	-	275,000	-	-	-	-	-	-	-	100,000	25,000,000
U OF FLORIDA	8,207	-	-	-	-	-	-	-	-	-	-	30,000	7,000,000

Name of Institution	Existing Sq. Ft. Research	1988 Under Negotiation Square Feet Space Renovated	New	Estimated Total Cost $	1990 Planned Square Feet Space Renovated	New	Estimated Total Cost $	1992 Planned Square Feet Space Renovated	New	Estimated Total Cost $	1995 Planned Square Feet Space Revovated	New	Estimated Cost $
U SO FLORIDA	2,289	-	110,000	9,715,000	-	12,000	1,320,000	-	-	-	-	-	-
GEORGETOWN U	440	6,000	17,000	4,600,000	15,000	-	3,000,000	7,000	-	1,400,000	7,000	-	1,400,000
G WASHINGTON													
HAHNEMANN M C													
HARVARD U	30,000	2,000	20,000	4,300,000	-	20,000	4,000,000	-	10,000	2,000,000	-	10,000	2,000,000
U OF HAWAII													
HOWARD U	500	-	-	-	200	-	7,000	500	-	12,000	-	-	-
U OF ILLINOIS	15,000	6,000	-	540,000	-	25,000	6,000,000	-		-	-	-	-
SO ILLINOIS U	500	1,000	-	200,000	-								
INDIANA U	5,000	20,000	2,000	1,400,000	-	-	-	-	4,500	1,000,000	-	-	-
U OF IOWA	4,694	1,634	1,000	356,930	500	1,000	275,000	1,000	1,000	386,000	1,000	2,000	620,000
JEFFERSON MED	4,000	-	-	-	-	5,000	1,000,000	-	-	-	-	-	-
JOHNS HOPKINS	28,067	-	30,800	3,696,000	30,000	90,000	16,500,000	30,000	-	3,000,000	60,000	-	6,000,000
U OF KANSAS	12,600	-	-	-	4,000	-	150,000	4,000	-	50,000	4,000	-	100,000
U OF KENTUCKY													
LOMA LINDA U	350	-	-	-	1,000	1,000	180,000	1,000	1,000	225,000	1,500	1,500	450,000
LSU NW ORLNS	57,000	-	-	-	-	25,000	1,800,000	-	-	-	-	25,000	2,000,000
LSU SHREVEPRT	500	-	-	-	-	1,500	150,000	-	-	-	1,500	-	150,000
U LOUISVILLE'	17,000	-	-	-	4	20,000	3,625,000	-	-	-	-	-	-
LOYOLA U	1,222	-	2,000	400,000	2,000	-	450,000	-	-	-	-	-	-
U OF MARYLAND	5,375	1,575	-	102,222	3,000	-	250,000	3,000	-	300,000	5,000	-	600,000
U MASS													
MAYO CLINIC	1,175	-	-	-	-	-	-	-	-	-	-	-	-
MEHARRY M C													
MED COLL GA	8,443	1,592	-	52,444	5,000	-	290,000	7,000	-	406,000	7,000	-	406,000
MED COLL OHIO	250	2,000	-	200,000	-	4,000	800,000	-	8,000	1,600,000	-	12,000	2,400,000
MED COLL PENN													
MED COL OF VA	8,500	-	-	-	2,000	-	195,000	-	-	-	-	8,000	3,000,000
MED COLL WISC	13,400	-	-	-	900	-	54,000	-	-	-	-	1,800	180,000
MED UNIV S C	10,000	-	10,000	2,000,000	-	10,000	2,000,000	-	-	-	-	-	-
U MED DENT NJ	17,000	-	26,000	4,000,000	-	26,000	4,000,000	-	-	-	-	-	-
U OF MIAMI	32,800	6,400	25,600	5,460,000	6,400	-	1,000,000	18,400	-	4,000,000	6,400	-	1,300,000
U OF MICHIGAN	40,000	-	-	-	-	-	-	-	-	-	-	-	-
U MINNESOTA	6,235	-	13,000	2,000,000	-	-	-	-	-	-	-	-	-
U MISSISSIPPI													

		1988			1990			1992			1995		
Name of Institution	Existing Sq. Ft. Research	Under Negotiation Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Revovated	New	Estimated Cost
U MISSOURI CO	8,500	-	400	$ 50,000	1,000	-	$ 5,000	-	-	$ -	-	-	$ -
U MISSOURI KC													
MT SINAI NYC	13,000	-	-	-	2,000	-	75,000	-	-	-	-	20,000	4,000,000
U OF NEBRASKA													
U NEW MEXICO													
NY MEDICAL C	5,300	-	-	-	-	-	-	-	-	-	-	-	-
NEW YORK U	11,000	-	-	-	3,000	5,000	4,040,000	5,000	-	60,000	7,000	-	100,000
U OF N C	1,400	-	-	-	400	-	160,000		-	-	-	7,000	2,800,000
NORTHWESTERN	7,000	1,800	4,000	1,415,060	-	-	-	-	15,000	4,437,750	-	-	-
OHIO STATE U	3,306	-	-	-	2,842	-	142,000	-	-	-	-	-	-
U OF OKLAHOMA	8,000	-	-	-	15,000	-	500,000	-	-	-	15,000	-	500,000
OREGON H S	5,975	-	82,000	20,500,000	-	-	-	-	20,000	4,500,000	-	-	-
PACIFIC P M C	1,700	-	-	-	750	-	75,000	250	250	87,500	250	250	87,500
PENN STATE U													
U OF PENN	14,000	4,828	-	757,109	2,000	2,000	1,000,000	-	-	-	-	-	-
U PITTSBURGH	13,200	-	-	-	2,000	-	434,000	-	8,000	1,824,000	-	5,000	1,455,000
U PUERTO RICO													
U ROCHESTER	9,100	500	-	62,500	1,250	-	168,750	1,750	-	253,750	2,500	-	400,000
RUSH M C													
U SO CAROLINA	1,000	2,500	-	58,000	4,000	-	80,000	-	6,000	1,200,000	2,000	-	238,000
STANFORD U	2,000	-	-	-	2,500	-	100,000	-	5,000	3,000,000	-	-	-
SUNY BROOKLYN	304	-	-	-	-	-	-	-	-	-	-	-	-
SUNY BUFFALO	10,000	1,500	-	60,000	5,000	-	250,000	-	20,000	2,000,000	-	-	-
SUNY SYRACUSE	2,200	-	-	-	5,000								
U TENNESSEE	4,000	-	-	-	-	-	-	-	-	-	-	-	-
TEMPLE U	-	-	-	-	1,600	-	192,000	800	-	23,400	-	-	-
TEXAS TECH U	9,243	2,000	-	200,000	-	35,000	2,500,000	-	-	-	-	-	-
U TEXAS GVSTN													
U TEXAS HSTN	9,000	-	-	-	2,000	-	200,000	2,000	-	200,000	5,000	-	500,000
U TEXAS S ANT	2,200	-	17,000	2,000,000	-	17,000	2,000,000	-	10,000	2,000,000	-	10,000	2,000,000
U TEXAS SWMS	9,000	-	-	-	6,000	3,000	600,000	-	9,000	800,000	-	9,000	1,000,000
TUFTS NE M C	3,900	4,300	-	400,000	1,200	-	111,600	1,200	-	111,600	-	-	-
TULANE U MED	9,371	627	-	56,930	-	3,500	350,000	-	-	-	-	-	-
U OF UTAH	5,800	-	42,100	7,210,000	-	-	-	-	-	-	-	-	-
VANDERBILT U	450	3,000	-	1,200,000	-	-	-	-	10,000	1,500,000	-	-	-

		1988			1990			1992			1995		
Name of Institution	Existing Sq. Ft. Research	Under Negotiation Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Renovated	New	Estimated Total Cost	Planned Square Feet Space Revovated	New	Estimated Cost
U OF VERMONT				$			$			$			$
U OF VIRGINIA	2,500	3,200	-	256,000	3,200	-	256,000	-	2,400	288,000	-	-	-
WAKE FOREST U	3,550	-	490	73,500	500	1,200	217,500	-	-	-	-	-	-
U WASHINGTON	12,941	-	-	-	-	-	-	-	4,000	700,000	-	4,000	800,000
WASH U (MO)	22,252	12,000	-	2,237,250	8,000	-	1,679,000	4,500	6,600	2,093,000	-	6,600	1,150,000
WAYNE STATE U	6,200	-	17,000	2,500,000	-	17,000	2,000,000	-	-	-	-	-	-
W VIRGINIA U	2,446	1,200	-	80,500	5,000	8,000	1,500,000	8,000	-	1,200,000	-	12,000	1,500,000
U WISCONSIN,	13,637	-	20,000	8,350,000	-	10,000	4,250,000	-	10,000	4,150,000	-	-	-
YALE U	27,805	450	-	45,000	-	8,900	2,765,000	-	-	-	-	-	-
TOTALS	959,226	122,248	614,524	$ 130,120,377	216,752	482,100	$ 128,450,250	155,863	237,750	$ 73,185,965	209,450	371,150	$ 100,309,000

TOTAL 1990-1995 $ 301,945,215

Senator CHILES. Thank you, Dr. Rubin. I am a strong believer in research, and certainly know how important it is to work with the eyes, and you are talking about some areas that are very close to me.

I have a son-in-law who is a juvenile diabetic, or was, and he is legally declared blind because of that. My daughter is a child of congenital cataracts from German measles, rubella measles. My grandson was a low birth weight baby and has lost his sight in one eye because of the vision there. So all of the things you are talking about basically are touching some of the research that touches those areas.

We find ourselves in a position which, in the way the money was divided up by the Appropriations Committee, we have less money than the President proposed in his budget. That is sort of an anomaly when this subcommittee has been fighting for 8 years or 7 years to keep cuts from coming in this area.

But it is just going to be impossible to make these kinds of increases with the kinds of dollars that we find ourselves with. We are going to have to pick and choose between trying to keep good programs, basically try to hold them where they are this time, but we believe very strongly in what you are saying. I think it is all money that is very, very well spent. I wish we had it all to spend.

We thank you.

Dr. RUBIN. Thank you.

STATEMENT OF ROBERT R. HUMPHREYS, EXECUTIVE DIRECTOR, NATIONAL COALITION ON IMMMUNE SYSTEM DISORDERS

Senator CHILES. Now we will hear from Mr. Robert Humphreys, the executive director of the National Coalition on Immune System Disorders.

Mr. Humphreys?

Mr. HUMPHREYS. Good morning, Mr. Chairman.

The National Coalition on Immune System Disorders is an organization comprised of a variety of voluntary and professional organizations that are interested in immune related disorders.

In terms of overall NIH funding for fiscal year 1989, the coalition would endorse the recommendations put forth by the ad hoc group on medical research funding, and that is $8.2 billion for NIH. In keeping with last year's recommendation by the ad hoc group, research project grants should be funded at an award rate of 41 percent, looking toward a 5-year goal of supporting research grants at the 50-percent level.

The NIH research institute most broadly involved with immune system research is NIAID. The President's budget for fiscal year 1989 requests $435.1 million for non-AIDS related research at NIAID, and $310.3 million for AIDS research, the NIAID portion of the consolidated AIDS budget assigned to the Assistant Secretary for Health.

We recommend the committee to recommend enactment of appropriations which reflect the ad hoc group's overall NIH recommendations, and that means in this case $874 million for NIAID, including $370 million for AIDS research. At that level, no reductions would be necessary in study section approved grants or research project grants and centers, and the Institute would be able to fund both AIDS clinical trials and AIDS research centers, and of course, other important research efforts in non-AIDS related immunology that could be expanded or initiated.

PREPARED STATEMENT

Appended to our testimony is a copy of the proceedings of the second annual meeting of the NCISD scientific advisory board for your review, and I would commend to you the information contained in it. Expert scientists in each of the disciplines represented on the coalition have participated in this joint effort for each of the past 2 years. I would also request, if it is possible, to have it appended to the hearings for Labor, HHS, Education appropriations this year, Mr. Chairman.

I will not take any more of the committee's time, and ask that the statement of the coalition be included in full in the record.

[The statement follows:]

STATEMENT OF ROBERT R. HUMPHREYS

Mr. Chairman and Members of the Committee, my name is Robert Humphreys. I am Executive Director of the National Coalition on Immune System Disorders(NCISD), an organization comprised of a variety of national voluntary and professional groups interested in the human immune system. The membership, mission of the organization, and the relationship of the member organizations to disorders of the immune system, are described in the attached brochure. My testimony will address funding requirements for the National Institutes of Health as they relate to the 65 million Americans with immune system disorders --diseases and conditions which include AIDS, allergies, diabetes, multiple sclerosis, arthritis, lupus, and a host of others.

Research efforts concentrated on AIDS will benefit the entire family of immune system disorders, and this Committee is to be commended for its support of AIDS research. At the same time, we urge that you work toward a funding level for NIH that will assure adequate research in all diseases and disorders of the immune system. Although the organizational members of this Coalition have disparate interests and objectives, they speak with one voice today in addressing research needs and the immune system.

In terms of overall NIH funding for FY 1989, the Coalition endorses the recommendations put forth by the Ad Hoc Group for Medical Research Funding; the total amount appropriated for the National Institutes of Health should be $8.2 billion. In keeping with last year's recommendation, research project grants should be funded at an award rate of 41%, looking toward a five-year goal of supporting research grants at the 50% level. The NIH research institute most broadly involved with immune system research is the National Institute of Allergy and Infectious Diseases. The President's budget for FY 1989 requests $435.1 million for non-AIDS research at NIAID, and $310.3 million for

AIDS research, the NIAID portion of the consolidated AIDS budget assigned to the Assistant Secretary for Health.

NCISD urges this Committee to recommend enactment of appropriations for NIAID which reflect the Ad Hoc Group's overall NIH recommendations. Specifically, we urge you to provide a total of $874 million, which amount includes $370 million for AIDS research. At this level no reductions would be necessary in study section-approved grant amounts for research project grants and centers, and the Institute would be able to fund both AIDS clinical trials and AIDS Research Centers. In addition, other important research efforts in non-AIDS related immunology could be expanded or initiated.

Two years ago NCISD established a Scientific Advisory Board whose mission is to provide expert scientific guidance to the Coalition, and through the Coalition to Congress and the public, on research directions and research needs with respect to immune system related diseases and disorders. The Board has been an invaluable and exciting addition to NCISD's activities and, we believe, will assist the members of this Committee to evaluate the myriad needs for research in this field. Appended to our testimony is a copy of the proceedings of the second annual meeting of the NCISD Scientific Advisory Board for your review and use. In brief the Board, which includes twelve nationally recognized experts in various areas of immune system research, recommends the establishment of a number of goals, and areas in which to concentrate research on a priority basis. NCISD believes these recommendations will be of inestimable value to this Committee as you develop your funding recommendations for NIH.

It is also important for the members of this Committee to understand some of the research currently underway as it affects the member organizations of NCISD. The Immune Deficiency Foundation notes that the expansion of knowledge of the primary immune deficiency diseases (those in which genetic and metabolic abnormalities result in a defect in one or more components of the immune system) has led to the development of several beneficial therapies. Among these are bone marrow transplantation and intravenous gamma globulin replacement. One of the severe combined immune deficiencies, ADA Deficiency, is the likely first candidate for correction by the new technique of gene therapy. The Lupus Foundation of America notes that immune system studies have led to the discovery of abnormalities that may be important clues to finding the causes of lupus. NIH research recently identified a new treatment for lupus patients with kidney involvement (lupus nephritis) who do not respond well to traditional drugs. The use of low-dose, pulsed, intravenous cyclophosphamide is more effective in treating the complication.

The Academy of Otolaryngology-Head and Neck Surgery notes the growing evidence that autoimmune mechanisms are implicated in an increasing array of hearing and balance disorders. It urges the committee to increase funding for basic research on the interactions between the immune and nervous systems, and to encourage interdisciplinary training of clinical investigators in this important new field. The Asthma and Allergy Foundation of America supports scientific research to discover the means to prevent and ultimately cure allergic diseases. Over the years a variety of medications have become available to treat the symptoms of asthma and other allergic disorders. However, even with significant advances in medical knowledge and treatment modalities, these disorders continue to undermine the health and well-being of a major segment of our population. The discreet manifestations of Sjogren's syndrome(SS), and the seemingly unrelated parts of the body in which the manifestations appear, present special problems for the researcher. Although theories exist as to the several factors involved in causing the syndrome, the actual cause of the dysfunction of the immune system is uncertain. Currently treatment is only palliative and not particularly successful.

The American Academy of Allergy & Immunology beleves the current rate of funding of research applications to the NIH is cause for alarm, as many meritorious applications go unfunded. The Academy wishes to express the need for research efforts and training of the new generation of researchers. The American College of Allergy and Immunology supports continued research on the immune system for the improved care of our patients. The Arthritis Foundation supports funding of about $224 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases for FY 1989 to fully continue the efforts of arthritis research. The National Multiple Sclerosis Society notes that research has evolved to the point where extensive clinical trials of promising immune system treatments are underway which may tilt the subtle balance toward control. The Clinical Immunology Society(CIS) is bringing the discoveries of the basic science laboratory into the arena of disease evaluation and treatment. For example, monoclonal antibodies, which are extremely valuable tools in clinical immunology, were first developed in the basic research laboratory from murine models. Now they are routinely used in evaluating disease states, and are beginning to be employed in the therapy of cancer and of organ transplantation. The American Diabetes Association notes that patients with insulin dependent diabetes are unusually subject to associated autoimmune diseases such as those affecting the adrenal gland cortex and gastric mucosa. The National Foundation for Ileitis and Colitis notes that research in inflammatory bowel disease, including ulcerative colitis and Crohn's disease, involves basic immunology in which development of pharmacologic agents may improve our understanding and treatment of the disease. The AIDS Action Council notes that the national attention focused on the AIDS crisis has brought about a vigorous climate for basic research in immunology and virology. Expansion of our research base is necessary to further delineate the pathogenesis and clinical manifestations of the disease, as well as the molecular biology of the virus. These and other research efforts will lead to improved understanding of the immune system and its many diseases.

Senator **Chiles**. We thank you, and we will see about making an appendix as you have mentioned.

The areas, again, of your interest are tremendously important. We recognize that, and we will try to do what we can to see that—to keep our research going in that area.

Mr. **Humphreys**. Thank you, Mr. Chairman.

Senator **Chiles**. Thank you, sir.

STATEMENT OF SAMUEL KATZ, M.D., INFECTIOUS DISEASE SOCIETY OF AMERICA

Senator **Chiles**. Now we will hear from Dr. Samuel Katz, from the Infectious Disease Society of America.

Dr. Katz?

Dr. **Katz**. Thank you, Mr. Chairman.

I represent the Infectious Disease Society, which is a group of physicians who take care of patients with infections, and obviously the infection which today receives most attention is AIDS. However, I think that you are aware that the mission of the National Institute of Allergy and Infectious Diseases covers more than AIDS. There is a budget for AIDS and there is a budget for non-AIDS related infections.

I couldn't help but be touched by your comment on your family members with congenital rubella and cataracts. In 1964 and 1965 we had 25,000 children born in this country with congenital rubella. In 1987 there were three, and that is because of the work of the National Institute of Allergy and Infectious Disease in developing rubella vaccines, and the Centers for Disease Control in seeing that those programs are carried forth.

I, too, will submit a statement which will be much more detailed, but I would like to call your attention to several features in the proposed budget which we feel the committee will pay attention to as you have in the past.

First of all, we feel it is not wise to consolidate AIDS funding outside the National Institute of Allergy and Infectious Disease. This will be administratively cumbersome. It will delay the process, and everyone is concerned about delay in our research, in our programs to help patients with AIDS.

PREPARED STATEMENT

Second, the amount of funding is inadequate and requires far more than people realize. I myself am an investigator of studies with children with AIDS, innocent victims who have AIDS. The clinical trials to take care of these children——

[The statement follows:]

STATEMENT OF SAMUEL KATZ

Mr. Chairman and members of the Subcommittee, my name is Samuel L. Katz. For the past 19 years, I have served as Chairman of the Department of Pediatrics at Duke Medical Center. I have been involved in research and policy in the area of infectious diseases for over 30 years. During that time, I co-developed the measles vaccine which is used throughout the world and have served as a member of several NIH study sections on infectious diseases. Duke currently is the recipient from the NIAID of three major research grants in the areas of pediatric AIDS and the development of vaccines for a number of infectious diseases, one training grant, three National Research Service Awards grants for fellows, and two FIRST awards for new investigators.

I am a member of the Public Policy Committee of the Infectious Diseases Society of America, on whose behalf I am testifying today.

I would like to take a moment to provide some background information on infectious diseases. The discipline is a subspecialty of internal medicine; in the near future, it will become a subspecialty of pediatrics as well. Simply put, infectious disease specialists focus on the interaction of the patient's immune system and the various organisms (viruses, bacteria, fungi etc.) which cause infections. This system is crucial to the healthy functioning of our bodies because it provides the necessary protection against these external invaders, as well as certain types of cancers. Without an immune system, we could not survive.

The Society comprises approximately 2,500 specialists in this field, including physicians involved in clinical and basic research in infectious diseases, as well as physicians who concentrate on clinical practice. As knowledge of viruses and their interactions with the immune system is relatively new and still growing, so is entry into the specialty, due in large part to the enormous increase in AIDS cases. Infectious disease specialists are the primary care physicians for patients suffering from this deadly disease, which attacks the entire body, not a specific organ.

Mr. Chairman, I appear before you today to discuss the Society's serious concerns with the Administration's budget request for the National Institute of Allergy and Infectious Diseases for Fiscal Year 1989. As a preliminary matter, I would like to thank members of this Subcommittee for their past support of the NIAID and AIDS research, training, and education. In past years, this Subcommittee has seen fit to approve significantly higher levels of funding for NIAID than the Administration has requested, and has also had the wisdom to reject the Administration's attempts to consolidate AIDS funding outside the NIAID, where a significant portion of AIDS research is conducted. We hope that you will do so again. We recognize that, as in years past, there is more demand than there are resources. However, we believe that there can be no more deserving cause than protection of the health of our nation by building upon the enormous strides being made in the area of infectious diseases, including AIDS.

The Splendid Work of the National Institute of Allergy and Infectious Diseases

The battle against AIDS continues to be a major priority of the nation. NIAID has served as a central focal point of the basic and clinical research in this area. We have come far in a relatively short time in understanding how this dread virus attacks:

- We have determined the way in which the human immunodeficiency virus connects to and destroys the cells of the immune system;
- We have discovered that the immune system's scavenger cells, while having the capability of being infected, are not destroyed. They are, therefore, harboring the virus and spreading it throughout the body;
- We have learned how the virus attacks the brain causing the neuropsychiatric problems witnessed in AIDS victims; and

- We have identified all HIV genes and have reproduced the virus, through recombinant DNA, for use in further research.

The NIAID has undertaken a number of projects to foster greater understanding of this elusive virus. It has established a reagent repository, which will be one of three in the world designated by the World Health Organization for the purpose of collection and dissemination of cloned HIV research materials. In addition, NIAID has established a Genetic Sequence Data Base for the collection and dispersal of genetic data pertaining to AIDS.

While these efforts are indeed significant, they are not sufficient. We continue to have a desperate need for finding ways to prevent and combat this disease. As you are aware, at present, only one drug, AZT, has been approved for the use in treatment of AIDS. Although this drug is a major breakthrough, it by no means constitutes the solution to AIDS treatment since it does not kill the virus, but only holds it in check. Also, in some individuals, it may have toxic side effects.

In addition to efforts to treat and cure AIDS, we continue in our quest for a vaccine against the virus. Phase I trials on a vaccine are currently underway at NIAID. Nevertheless, the research community is in general agreement that much remains to be done before a safe and effective vaccine against AIDS can become available.

While the national spotlight has been on AIDS, as it should for any national disaster, we must not overlook the important work being done by the Institute in other infectious diseases. We are firm in our belief that, while AIDS research and training must be appropriately funded, it must not be at the expense of activities in other crucial areas.

For example, we laud NIAID's support of research on new vaccines for other infectious diseases. We anticipate that soon there will be vaccines to protect the Third World against such devastating diseases as malaria and leprosy, and look forward to the day, in the not too distant future, when a new pertussis vaccine with fewer side effects than the one currently available is developed. We need only look to the new hepatitis B vaccine to know that availability of newer and safer vaccines can be a reality.

In addition to NIAID's vaccine efforts, we commend the Institute's important work in the development of anti-viral substances to combat a variety of viral diseases such as influenza and herpes.

Finally, we wholeheartedly support NIAID's efforts in the area of sexually transmitted diseases, such as research into pelvic inflammatory disease.

Recommendations of the Infectious Diseases Society

1. Consolidated AIDS Account

Unfortunately, the IDSA finds itself once again in a position of fighting against Office of Management and Budget proposals to restructure the means of appropriating funds for the Department's efforts to eradicate AIDS. The FY 1989 budget request, as in years past, envisions the placement of all AIDS money in an account under the Office of the Assistant Secretary for Health. While central governmental oversight of the nation's AIDS activities is essential, adoption of the OMB proposal will seriously hamper ongoing and future research and training efforts. For the following reasons we believe AIDS funds appropriated for activities of NIAID be provided directly to the Institute, and not to the Assistant Secretary.

First, time is of the essence in research. If the AIDS money intended for NIAID programs is placed in the OASH budget, the ability to fund research efforts will be considerably slowed: an extra layer of bureaucracy would be added to the process of distributing those funds, and monies may not be released when needed. We envision several months' lag time from the point at which money is requested until it is released. When faced with a national epidemic, these months could prove to be crucial.

Moreover, administratively, the proposal places the Institute in an awkward position: while NIAID will be overseeing extramural and intramural research on AIDS, the salaries of its scientists would, under the proposal, be in the OASH budget. This is clearly contrary to good management principles.

Thus, we urge this body to reject once again the Administration's proposal to consolidate the AIDS monies, and to allow NIAID to receive its appropriation directly.

2. NIAID's Fight Against AIDS

Although sums appropriated for NIAID's contributions to this nation's efforts against AIDS have increased significantly over the past several years, even greater support is necessary. Previous assumptions as to the time, cost and number of patients needed for clinical trials, which have been based on trials involving other infectious diseases and cancer, have proven to be incorrect. It is now clear that clinical trials involving AIDS will be much more time consuming and, hence, more costly than predicted. Moreover, additional clinical trials, involving both adults and children, must be conducted.

Specifically, the IDSA recommends appropriations to the NIAID in excess of those requested by the Administration for AIDS-related activities as follows:

- $30 million for grants in AIDS research, of which we believe two-thirds, or $20 million, should be for the support of clinical trials.
- $10 million in additional funding to support the NIH Plan for AIDS Vaccine Development and Evaluation.

3. Non-AIDS Funding Issues

The Administration's budget request calls for an astonishing decrease -- by approximately 50 grants -- in the total number of competing research grants that would be awarded by the Institute. The impact of this cut would be devastating to the research community. Moreover, while the budget request appears to continue funding of research grants at the current payline of 140, it does so only by cutting an average of 14 percent per grant from the amounts recommended by study sections. NIAID's award rate for approved research grants has historically been lower than the average for the NIH as a whole, despite the recent emphasis on AIDS. This inequity can be rectified only by increasing funding for research grants.

In addition, the Society believes that the budget request for clinical training of physicians and research scientists is insufficient to support opportunities of the growing number of members of the infectious diseases community to make major strides against infectious diseases.

Specifically, the Society makes the following recommendations for the non-AIDS activities of the Institute:

- The NIAID budget should provide for full funding of 1,270 non-competing, non-AIDS research project grants. The Administration's budget is predicated upon an 8 percent, per-grant reduction in such grants.
- We recommend sufficient appropriations to fund 750 competing non-AIDS research grants. Appropriations of $131 million are necessary to accomplish this result. This would offset the proposed reduction in such grants and instead increase last year's number by 225 grants.
- We urge that Congress appropriate sufficient monies to fund 600 non-AIDS full-time training positions. This would require an appropriation of approximately $16 million, as compared to the $12.9 million budget request, which would accommodate only 485 such research trainees.

Mr. Chairman, the Society believes that only through the increase in appropriations recommended above can the NIAID meet its stated goals for advances in research and training for infectious diseases, including AIDS.

On behalf of the infectious diseases community, thank you again for your continued support for NIAID's work, and for biomedical research and training. I will be happy to answer any questions you or the other members of the Subcommittee may have.

Senator CHILES. Doctor, you are right there, the problem is there is not enough money, but there is the additional problem of how wisely can you spend additional money?

Now, you know, I see this problem in star wars, I vote to restrain the spending in SDI because I think we are putting too much money in. I am one of the strong proponents in trying to put in the amount of money that we can properly—and I say properly spend in AIDS. But you know, like me, Doctor, when AIDS is the new thing on the block, everybody is thinking up a project that they can have to be involved in AIDS. And the numbers, as far as the number of projects out there, there is no amount of money that would fund them all.

But someone has to make a decision as to how much of these new dollars—and if you look, there has been no disease ever known to man that we have pumped money into the way we have AIDS.

Now, I think that is wise. I hope 15 and 20 years from now we will look back and think it was wise, and it was an effective and efficient way of spending the money that we put in.

Dr. KATZ. I am glad that you are looking after my tax money, because I agree with you, but I think you also appreciate that more has been learned in 7 years since the disease was discovered, in 4 years since the virus was discovered, than with any other infectious disease in the history of man, and that is because you have invested in the past in the National Institutes of Health, and specifically in NIAID.

The backlog of scientific development which has enabled us to move so rapidly with AIDS is the payoff of that past investment, and I agree with you, I do not want to rob Peter to pay Paul, and there are lots of other infectious diseases which need attention, diarrheal disease, meningitis——

Senator CHILES. Well, we are robbing Peter to pay Paul in AIDS right now. There is no question of whether we should; we are doing that.

Dr. KATZ. But I think you can have confidence in the peer review system of the National Institutes of Health that these specific dollars are going to be spent wisely because of the critical peer review that has to judge the grant applications. They will not be squandered. These are dollars that will be spent wisely, and believe me, the clinical trials are far more costly than anyone realizes. It has cost us approximately $25,000 per child per year for the clinical studies with azidothymadine, and those haven't even been borne by NIAID but in part. Our hospital has paid part. Burroughs Welcome Co. has paid part. So that we are into a very costly business but I think the results that you may have read in the paper that were announced just several days ago of the adult studies, 74 percent of the people who have been on AZT are alive 2 years after starting the drug. Those who didn't receive the drug, more than one-half, are dead.

So we are moving in the right direction, but it is very costly, sir.

I appreciate your caution, and I also appreciate your giving me the time to respond to you.

I would only ask that you read the statement, you and your committee members.

Senator CHILES. We shall.

Dr. **Katz**. And that you work judiciously as you have in the past, and we are very grateful for that.

Senator **Chiles**. We thank you, especially for the work that you are doing. To me, the most innocent of the innocent is the children that are the victims of AIDS.

Dr. **Katz**. Thank you. I hope you do remember that.

STATEMENT OF R. BARRY SLEIGHT, NATIONAL CHRONIC EPSTEIN-BARR VIRUS INFECTION ASSOCIATION

Senator **Chiles**. Now we will here from Barry Sleight, for the National Chronic Epstein-Barr Virus Infection Association.

Mr. **Sleight**. Thank you, Mr. Chairman.

Mr. Chairman, I present testimony today as an individual patient with chronic fatigue syndrome, or CFS, and on behalf of 275 patient groups and national organizations involved with this disease, formerly called chronic Epstein-Barr virus syndrome, or CEBV.

In March, the CDC issued a new working case definition for chronic fatigue syndrome, which is the new name. This definition includes 18 major signs and symptoms such as fatigue, fever, sore throat, swollen and painful lymph nodes, pain, mental confusion, and sleep disturbances. This definition is narrow for research purposes, and there are over 20 other symptoms listed in medical literature.

Our patients have many symptoms. Many are bedridden for months at a time. Society pays many social and economic costs. Patients have difficulties in obtaining Social Security disability benefits. And there has been increasing public attention and media coverage focused on this disease.

Medical journal articles and media suggest this disease is concentrated in certain areas; certain groups have a higher incidence, and CFS has increased dramatically since the early 1970's. Recent research shows an urgent need for greater public health response to this disease.

The New England Journal of Medicine reported deaths of patients with this disease from development of cancer. Chronic fatigue syndrome is killing Americans.

Medical literature has shown measureable cognitive function deficits and brain changes in CFS patients like those found in multiple sclerosis or AIDS. This disease is destroying the minds of Americans.

Medical journals have reported serious eye disease in chronic fatigue syndrome. This disease is causing blindness in Americans.

Most disturbing is the finding that CFS is an immune system disease. Immunologic irregularities have been documented, including irregularities in immune system parts of B cells, T cells, interferon and especially natural killer cells. A number of infectious agents have been suggested as being involved, including the new human herpes virus VI linked, by Dr. Gallo at the conference in Miami Beach 2 weeks ago, with AIDS.

Current thinking, as to cause, suggests these agents are merely representative of an underlying disease of the immune system. The wide range of symptoms, cancers, brain changes and so on are all consistent with this. The trend of research now points toward a single infectious disease process involving the immune system.

Public health response to CFS is welcome, but should be increased, consistent with a serious disease.

We have a number of recommendations to the Congress for HHS activities related to chronic fatigue syndrome as contained in my full statement, including the inclusion of CFS within those programs involving disorders of the immune system, the designation of CFS as a priority disease program by the NIH, and the provision more funds for research. CDC has included funds to continue an expanded CFS surveillance program and related research with six FTE's plus $945,000 for equipment and staff support.

PREPARED STATEMENT

The Congress has had a significant impact on understanding this very serious disease. We ask that these efforts continue toward the time when America is rid of chronic fatigue syndrome.

Senator CHILES. Thank you very much for your testimony. We appreciate your appearance here.

Mr. SLEIGHT. Thank you.

[The statement follows:]

STATEMENT OF R. BARRY SLEIGHT

Mr. Chairman, I am presenting this testimony as an individual patient with Chronic Fatigue Syndrome, or CFS, and also on behalf of 275 patient support groups and national organizations actively involved in matters related to this disease. This disease is also known by several other names, including Chronic Epstein-Barr Virus Syndrome, or CEBV.

The 1988 Labor-HHS-Education Appropriations Bill was accompanied by a report, number 100-189, which contained language with regard to this disease. The Committee urged the National Institute of Allergy and Infectious Diseases to expand the level of grant awards and research support for this disease. In addition, the Centers for Disease Control was funded to begin a surveillance network to suggest the national incidence of this disease, and the Committee encouraged the expansion of this network and related research support.

In March the CDC issued a new Working Case Definition for Chronic Fatigue Syndrome via an article in the Annals of Internal Medicine. This article also established the usage of the term Chronic Fatigue Syndrome for this disease within the Public Health Service.

This definition includes many of the major symptoms that our patient population suffers with: severe fatigue, mild fever, sore throat, swollen and painful lymph nodes, muscle weakness and aches, fatigue after exercise, headaches, joint pain, sensitivity to light, spots in the field of vision, forgetfulness, excessive irritability, confusion, difficulty thinking, inability to concentrate, depression, and sleep disturbances. This Working Case Definition is intentionally made very narrow for biomedical research purposes, and it is important to note that there are many other symptoms, over twenty, listed in the medical literature for this disease.

Practically all of our patient population have many symptoms. Many are bedridden for days, weeks, or months at a time. Our society is already paying such social and economic costs of this disease as lost jobs, broken homes, lost productivity, lost tax receipts, bankruptcies, and increased health care and disability costs.

A typical pattern is one in which a person becomes sick with Chronic Fatigue Syndrome, and is quickly fired from work or forced to resign. The person often then has no health or disability insurance at a time of medical expenses that may run into many thousands of dollars. Financial ruin results.

Our patient population also has encountered a variety of difficulties in obtaining Social Security disability benefits, a problem also of concern for Congressional caseworkers, who have received numerous requests from constituents with CFS for assistance in receiving Social Security benefits.

In the past several years there has been increasing public attention to this disease problem. Media coverage has included at least one item in practically every national television newsmagazine show and major newspaper, as well as articles in dozens of national magazines. The CDC has received several thousand inquiries related to this disease since late 1985. There is as yet no government data on incidence of Chronic Fatigue Syndrome, but several medical journal articles and numerous reports in the popular media suggest that this disease is concentrated in certain geographic areas around the country, that certain groups have a higher incidence, and that CFS has increased in incidence dramatically since the early 1970s.

Further, in recent years there has been an increase in information from the biomedical research community in areas related to CFS. I will illustrate the urgent need for a greater public health response to this disease by noting some of this information, informed by reports from our patient community.

An article in the respected New England Journal of Medicine in March reported on the deaths of some patients with this disease from later development of T-cell lymphoma, a type of cancer. As illustrated by this article, Chronic Fatigue Syndrome is already killing Americans.

Numerous reports in the medical literature have documented a variety of measurable cognitive function deficits, as well as mental confusion, memory loss, difficulty concentrating, and depression in patients with CFS. Also, one existing medical journal article and another in preparation document brain damage in patients with CFS. These brain changes are very similar to some of those found in patients with multiple sclerosis or the Acquired Immune Deficiency Syndrome, or AIDS. Taken together, these findings raise the spectre for the future of thousands of Americans with serious impairment in their mental and intellectual functioning. This disease is already destroying the minds of Americans afflicted with it.

Chronic Fatigue Syndrome also involves serious eye disease. Medical journal articles last spring in the Archives of Ophthalmology and the American Journal of Ophthalmology reported multifocal choroiditis and uveitis in patients with CFS. This disease is causing blindness in Americans.

Perhaps most disturbing, from a larger public health perspective, is the finding that CFS is a disease which involves the immune system. A number of medical journal articles have documented a variety of immunologic irregularities and associated metabolic defects in CFS patients. Irregularities in the immune system components of B-cells, T-cells, and interferon have been reported. Also, a November article in the Journal of Immunology showed that one subset of a key immune system component, the

Natural Killer or NK-cells, is nearly absent in CFS patients. These Natural Killer cells are one of the body's first lines of defense against cancer; when there is a defect here, there is a greatly increased risk of cancer.

Over the past several years a number of infectious agents have been suggested within the biomedical research community as being possibly being involved in some way in Chronic Fatigue Syndrome, including:

Epstein-Barr virus;

Human Herpesvirus 6 (HHV-6), also known as HBLV;

an adenovirus;

Rubella virus strain RA27/3, from the new, more powerful rubella live virus vaccine introduced into the U. S. in 1979; and,

an enterovirus of the Coxsackie group.

My understanding of the current trend of thinking within the biomedical research community as to the cause of Chronic Fatigue Syndrome suggests that these infectious agents may be merely representative of the multiple associations and multiple effects of an underlying disease of the immune system. For example, the Epstein-Barr virus has long been associated with a variety of disease in patients with suppressed immune function. The wide range of symptoms that CFS patients show, involving all systems of the body, are consistent with an underlying disease of the immune system. An increased incidence of rare types of cancer is consistent with an underlying disease of the immune system. Brain changes and cognitive function problems are consistent with an underlying disease of the immune system.

At the national convention of the American Society for Microbiology two weeks ago, Dr. Robert Gallo of the NIH, the co-discoverer of the AIDS virus, reported that the major co-factor in immune system destruction in AIDS, Human Herpesvirus 6 or HHV-6, is suspected to play a role in Chronic Fatigue Syndrome. The current trend of biomedical research into Chronic Fatigue Syndrome now points toward the presence of infectious, etiologic agents causing an underlying disease of the immune system.

The Federal public health response to date to Chronic Fatigue Syndrome has been welcome, but should be dramatically increased to be in concert with a serious immune disease. We are pleased that the National Institute of Allergy and Infectious Diseases, at the urging of the Congress, has conducted and funded small amounts of biomedical research into CFS.

We are concerned that the activities of the Centers for Disease Control regarding CFS have not to date been consistent with a new epidemic of a disease of the immune system. The only major activity of the CDC in this Fiscal Year related to CFS has been due to the specific direction of the Congress. I have discussed the new Working Case Definition above; on April 15, the CDC issued the solicitation document to hire a management contractor to conduct the surveillance network for CFS. The document notes that "the major justification for initiating surveillance for CFS is to address public health concerns about a possible epidemic of the syndrome in the U. S."

We offer a number of recommendations to the Congress to improve activities of the Department of Health and Human Services related to Chronic Fatigue Syndrome, as follows:

--- To improve the overall management of this public health matter, the Public Health Service should include CFS within all those PHS programs in fulfillment of the current mission involving disorders of the immune system.

--- The National Institutes of Health should designate Chronic Fatigue Syndrome as a Priority Disease.

--- The National Institute of Allergy and Infectious Diseases should be encouraged to expand its research on Chronic Fatigue Syndrome toward finding better diagnostic techniques, better treatments, and, hopefully, a cure. Research should be expanded on the role of Human Herpesvirus 6 (HHV-6) in the context of CFS. A minimum of $5,000,000 from already-allocated funds should be applied to CFS research, and a minimum of $500,000 from the already-allocated funding in the Small Grants Program should be applied to CFS research. Grants issuances for CFS research should be expedited.

--- The Centers for Disease Control should be funded to continue and expand its CFS surveillance program and to conduct research and studies, including case-control, etiology, risk factor, and control mechanism studies related to CFS. CDC should report to the Congress on a timely basis as to its progress with this work. The CDC should be funded with 6 FTEs plus $945,000 for equipment, staff support, and patient studies for this work.

--- In an effort to improve the ability of CFS patients to receive Social Security disability benefits, the Social Security Administration should be directed to report to the Congress concerning better definitions of eligibility for CFS patients.

Progress is being made in the understanding of this disease; sadly, much of what has been learned in the past two years indicates that Chronic Fatigue Syndrome is a very serious disease indeed.

The interest and efforts of the Congress have had a significant impact on this better understanding; we ask that these efforts continue toward the time when America is rid of this disease.

STATEMENT OF ROBERT T. SCANLON, M.D., GEORGETOWN UNIVERSITY MEDICAL CENTER, JOINT COUNCIL ON ALLERGY AND IMMUNOLOGY

Senator CHILES. Now we will hear from Dr. Robert Scanlon of Georgetown University Medical Center, Joint Council on Allergy and Immunology.

Dr. SCANLON. Thank you, Mr. Chairman.

Senator CHILES. How do you do, Dr. Scanlon.

Dr. SCANLON. Fine. I am Dr. Robert Scanlon. I am an allergist and pediatrician. I am on the faculty of Georgetown and have a practice in allergy in Bethesda, and I am here to represent the Joint Council of Allergy and Immunology which briefly is a nonprofit organization that represents 3,500 allergists and immunologists, and particularly is concerned with patient education and with the encouragement of training programs and research awards.

As the National Coalition of Immune Diseases has advocated, we, too, advocate the appropriation put forth by the ad hoc troup for medical research for the NIH in general, and for the National Institutes of Allergy and Infectious Disease in particular, for $980 million.

We are all astounded by the explosion in medical knowledge that has gone by in the past 25 years in science in general, and medicine in particular, infectious disease and allergy specifically. All of this medical knowledge has allowed the practitioners to give better care to the patients, but what I really want to particularly emphasize today is the fact that none of this advancement would have been possible if it wasn't for the appropriations by this committee.

In listening to what has been said previously, I realize that many of us feel that each of our projects is of extreme importance, and I suppose in medicine, which concerns life, it is. So, I am here today to emphasize the many asthmatics, atopic eczema patients, as well as the infectious disease part with our rheumatoid patients, et cetera.

PREPARED STATEMENT

I am here to thank the committee for past appropriations, and I suppose that each year we will be coming back and saying we have more unanswered questions, and we need more and more, and that is good. Maybe someday I will be able to come and say we don't need it.

So thank you, Mr. Chairman.

[The statement follows:]

STATEMENT OF ROBERT T. SCANLON

Mr. Chairman and members of the Committee, I want to thank you for the opportunity to allow me to present testimony on behalf of the Joint Council of Allergy and Immunology (JCAI). I am Robert Scanlon, a physician, an allergist, and a member of JCAI.

The JCAI was incorporated in 1975 in the State of Illinois to serve as the socio-economic and public education arm of the American Academy of Allergy and Immunology and the American College of Allergy and Immunology. We are a not-for-profit corporation representing over 3,200 allergists and immunologists. The membership is representative of both clinicians and researchers.

The numbers I opened my testimony with are statistics. They do not tell you much of anything about these people, their disease, their treatment nor the chances of a cure. It does not tell you if this number has decreased or increased over the year, and it does not tell you the why or the what of the diseases.

But, it does dramatize the seriousness of the diseases we, as physicians or researchers in allergy and immunology try to treat or find the answers for everyday.

Over the past year, funding for the National Institute of Allergy and Infectious Disease has provided some important research breakthroughs both in finding some answers for cures and in providing better treatments. Our field is on the cutting edge of basic biomedical science and is one of the fastest moving areas.

For example, recent breakthroughs in research indicate that we may soon be able to identify a genetic predisposition to allergic conditions. Such a finding brings us that much closer to curing these conditions.

Other research has lead us to developing new approaches that would involve gene therapy that could later help us deal very specifically with the treatment of diseases.

Some of the more recent developments or breakthroughs that have come about because of NIAID funding are:

o the new and improved drugs like inhaled steroids in the treatment of asthma, a drug that could prevent the progression of shingles in an infection, and a new drug to treat the Herpes virus in children.

- new vaccine developments that are now being tested in clinical trials such as the improved pertussis vaccine, a H. Flu. Meningitis vaccine, and a Hepatitis vaccine, and vaccines that could prevent severe diarrhea in infants.

May I only say, that the JCAI commends your work and is thankful for your past support and consideration. This year **the JCAI requests continued and increased funding for the National Institute of Allergy and Infectious Disease (NIAID) at the National Institutes of Health (NIH). JCAI supports the recommendations of the Ad Hoc Group for Medical Research for an appropriation level of $8.4 billion for all the NIH.**

More specifically, we urge the Committee to recommend $980 million in FY 89 for the NIAID. This budget reflects a $235 million increase in money from the President's budget.

This funding level would allow at least 50% of the approved NIAID research grants to be funded. In our estimation, that would allow 910 new grants to be researched. Current estimates show that in Fiscal Year 1988 NIAID is only able to fund 32% of the grants that have been approved for funding.

If NIAID were funded above the President's budget, the following are examples of other research projects that could be undertaken:

- defining criteria to access the disease status of therapeutic need of patients with systemic lupus erythematosus
- determining the immediate and long term benefits of optimal medical intervention versus traditional care of childhood asthma
- more basic research regarding the genetic bases of autoimmune diseases such as Graves disease, multiple sclerosis and diabetes
- development of joint research efforts between engineers, basic immunologists and clinicians to translate new

information into the development of medical devices for organ transplantation

- investigations and studies to determine the factors responsible for the recent increase in asthma deaths

Medicine without research is like cars without gas. The effectiveness of one is negligent without the active participation of the other.

JCAI supports research in every aspect. But good research is only available with an adequate number of well trained researchers. Both the National Academy of Sciences and the National Science Foundation have recently released data which indicates a shortage of biomedical scientists and they are predicting that this shortage will be felt into the future.

Training of biomedical researchers requires a minimum of 8 to 10 years after a baccalaureate education. We are in urgent need of the funds for training programs today. The United States is a leader in biomedical research. We will not remain a leader if the individuals capable of handling this research are not at hand.

JCAI encourages this Committee to place an emphasis on training programs and research awards in order to meet our training needs.

The President's budget allows for 509 training slots under NIAID which would include "AIDS" slots. We believe that 624 training positions including those for "AIDS" is what is necessary to meet the needs of our field.

9 million people suffer from asthma. 4,000 to 5,000 will die as a result of an asthma attack.

14 million people suffer from hayfever.

15 million people suffer from food allergies, skin allergies, drug allergies and insect stings.

TOTAL: 35 million -- your neighbors, your friends, and your relatives who suffer from allergies or a breakdown in their immune system. This means that one out of every nine Americans suffer for an allergic or an immune disorder.

Thank you for the opportunity to meet with you today. I would be happy to answer any questions.

Senator CHILES. Thank you very much, Doctor.

Let me ask you, one of the concerns that is really striking me is that in cancer research—I use that just because that is the example that has come before us—less than one-third of the doctors that are out there are using the latest developments that NIH and other research bodies have come up with. That particularly distresses me because here we are putting all this money in, and many of the things that they are coming up with will save or prolong lives, they certainly will ease lives, and to find that out there in practice we still have doctors that are not using the latest developments—how would that relate in your field of infectious diseases, allergies?

Dr. SCANLON. Well, of course, this is a moot point. The question is, Why do they not have the information? And I think that this is an individual problem and an individual position in keeping up, and we are all expected to keep up, and then the question is, How well does the NIH disseminate their information?

Now, in the allergy and asthma and infectious disease field, we do seem to have good public programs. Lay people are included, and there are various programs for the lay people and for people with particular conditions.

So I would say that there has to be more dissemination and better dissemination, and there has to be more acceptance on the part of the—more motivation on the part of the practicing physician.

Senator CHILES. Well, certainly NIH has to disseminate and has to do everything they can in that area, and we are going to try to monitor that, but there has to be, I think, tremendous push by the medical societies and others to see that the practitioner out there is trying to keep up and is keeping track of developments, because if not, we are not getting our money's worth by a long shot.

Dr. SCANLON. Well, we are all required to have basic CME credits, so we are required to attend courses and lectures, and there are many societies like the American College of Allergy or the American Academy of Allergy and Immunology that put on programs, and they are well attended.

So I am surprised at the figure of one-third in cancer. I wouldn't feel that——

Senator CHILES. I was very surprised at it, too, Doctor, shocked.

Dr. SCANLON. I would not feel, honestly, that that is the case in allergy and infectious disease.

Senator CHILES. Thank you, sir. I appreciate your testimony.

Dr. SCANLON. Thank you.

STATEMENT OF ALFRED A. BAUMEISTER, PH.D., DIRECTOR, JOHN F. KENNEDY CENTER FOR RESEARCH ON EDUCATION AND HUMAN DEVELOPMENT, VANDERBILT UNIVERSITY; ON BEHALF OF AMERICAN ASSOCIATION ON MENTAL RETARDATION, AMERICAN ACADEMY ON MENTAL RETARDATION, AMERICAN PSYCHOLOGICAL ASSOCIATION, DIVISION ON MENTAL RETARDATION

Senator CHILES. Now we will hear from Dr. Alfred Baumeister, the director of John F. Kennedy Center for Research on Education and Human Development.

Dr. Baumeister?

Dr. **Baumeister**. Thank you, Senator.

I am Al Baumeister, director of the John F. Kennedy Center at Vanderbilt University. It is 1 of the 12 national Mental Retardation Research Centers.

I represent the American Association on Mental Retardation, the Academy on Mental Retardation, the American Psychological Association. We are grateful for this opportunity to appear before the committee to share our views on funding for mental retardation and research related to developmental disabilities through NICHD.

Senator, I know that you share some of our concerns through a recent publication of yours that appeared in the American Psychologist.

There are over 350 known causes of mental retardation. Over 6 million people, children and adults, are affected. The community and residential services alone this year will cost over $10 billion, just for residential services. Yet, the national research capability today is less than one-half of what it was in 1975, and continues to erode.

In 1987, from a budget of $309 million, NICHD expended a total of only $54 million on projects dealing with mental retardation. In fiscal year 1988, the NICHD appropriation was increased on paper to $397 million. The actual expenditures were much smaller because subsequent downward negotiations were 11 percent for noncompeting grants, 12 percent for competing grants, and 17 percent for research centers. This followed on the heels of downward negotiations of 9.5 percent in 1987.

Now the administration proposes a budget of $418,388,000 for fiscal year 1989. Under the fiscal year 1989 proposed budget, funding rates for grants would be only 23 percent and would also force the elimination of a mental retardation research center, also including a 16-percent cut.

I understand that budget deficits of the magnitude that we face cannot continue. But there are choices, and reductions in health services, including research, hurt children, mothers, and families. The question must be raised, Is this what we intend in the name of public policy?

PREPARED STATEMENT

Our recommendations are as follows: increase NICHD appropriation to $486,425,000 in contrast to the administration request for $418,388,000; second, provide full funding for the research centers, eliminating the negotiated reductions. Furthermore, centers not funded under the fiscal year 1989 administration request should be restored.

In our written statement we have more extensive recommendations, and I thank you, Senator.

[The statement follows:]

STATEMENT OF ALFRED A. BAUMEISTER

Mr. Chairman, my name is Alfred Baumeister. I am Director of the Kennedy Center at Vanderbilt University, one of the 12 national Mental Retardation Research Centers. I represent the American Association on Mental Deficiency, the American Academy on Mental Retardation, and the American Psychological Association. We are grateful for the opportunity to share our views concerning federal support, through NICHD, for research on mental retardation and related disabilities.

Mental retardation typically is a life-long disability with social, psychological, and biological causes, ranging from mild to extremely severe consequences. There are over 350 different causes of mental retardation, including genetic conditions, disorders of metabolism, problems of pregnancy and birth, brain damage due to a large number of teratogens, accidents, and other untoward circumstances that affect development, such as poverty, undernutrition, and lack of adequate psychological and social stimulation.

The human and financial costs to society of mental retardation are staggering. No other human affliction creates so much suffering, for so long, and at such great consequences to the individual, the family, the community, and our nation. There are approximately 6,600,000 retarded persons in the United States. To provide care and habilitation to the 100,000 persons who reside in public institutions in 1986 we spent over $4.6 billion. The variety of special programs in the community represents an enormous outlay as well, running about $4.4 billion in 1986. There are now many thousands of babies who will never have a chance, for even part of their lives, to share in the ordinary opportunities and challenges that we here enjoy.

Because the Congress earlier responded to the chronic needs of children, we have made scientific progress over the past 25 years toward the goals of prevention and amelioration. Some research knowledge has been put into practice with outstanding results. For example, we understand the biochemistry underlying a few genetic disorders. We are now able to create medical and environmental conditions for people only two decades ago who would have been profoundly retarded and who are now able to live normal lives. Equally importantly, studies of behavior and social processes have enabled us to develop effective educationally based procedures that ameliorate many of the learning and behavior problems associated with mental retardation.

Yet we cannot become complacent. We have not solved the problems of developmental disabilities. Far from it. Despite advances in our understanding of mental retardation, the truth is that in vast majority of instances we do not know what specially causes retardation or how to prevent it. One fact should be made abundantly clear: mental retardation in most cases cannot be traced to a single specific biomedical cause. Indeed, some forms of morbidity among children are on the increase.

Between 70% and 80% of the cases are linked to psychosocial disadvantage. In 1985, 14.0% of our population, including 20% of our children were below the poverty line. As you are aware, minority groups are differentially represented. According to the government's 1985 data, 43% of black children and and over 40% of Hispanic children under 16 years lived in poverty. There is still age bias associated with poverty. Children are the victims. The 1985 data for poverty rates reveal the following: 23% among preschool children, 20% among school-age children, 12.2% among adults, non-elderly, 12.6% among the elderly. Poverty is not a wholesome condition for rearing children. Mental retardation does not cause poverty, but poverty contributes significantly to mental retardation and other forms of childhood morbidity. We require a much stronger biomedical and behavioral research base from which to proceed toward treatment and prevention.

Yet, since 1974, commitment to mental retardation research has deteriorated. For 14 years I have conducted analyses of NICHD funding patterns with particular reference to the status of mental retardation as a priority. One general and compelling conclusion emerging from these analyses is that funding for mental retardation research, both in absolute and relative terms, is in a much less favorable position today as compared with 14 years ago. In 1988 dollars, our research capability is less than half what it was in 1975. Attached are a table and a figure showing a continuing decline in relative support for mental retardation research, from 1972 to 1987. These tabulations are based on the budget of the NICHD's Center for Research on Mothers and Children (CRMC). This is the organizational unit that carries the NICHD obligation to support of mental retardation research.

In 1987, out of a budget of about $309 million NICHD expended a total $54 million on research projects dealing with mental retardation, or about 17%. In FY1988 the appropriation was increased to $397 million. But downward negotiations were set at 10.7% for noncompeting grants, 12% for competing grants, and 17% for the research centers. This followed on the heals of downward negotiations of 9.5%

in FY1987. We do not believe that this is the kind or level of response consistent with either: (a) Congressional intent in creating the NICHD, (b) the gravity of the problem of mental retardation in human and financial terms and, (c) the public welfare. When one considers that the inflation rate exceeded 160% over the past 10 years, we have reached a severe crisis point for research funding of gravely serious health and social problems.

The 1987 appropriations for the Institute was $309,225,000 and in 1988 $396,811,000. Now the Administration proposes an NICHD budget of $418,388,000 for FY 1989. That includes $20,000,000 now specifically targeted on AIDS research. Under the FY 1989 proposed budget the funding rate for grants would be 23.2% as opposed to 26.6% in FY 1988. This is the lowest rate among the NIH Institutes. Another feature is that the President's budget would cut the number of NICHD research centers from 44 to 41, one of which would be a mental retardation center. Even given that tragic development, the remaining centers would be cut another 16% in core support--this on top of cuts of the 9.5% suffered in 1987 and 17% in 1988.

We understand, of course, that enormous deficits in the U.S. budget cannot continue and that adjustments must be made. But, reductions in health services, including research, hurt people--children, mothers, families--and the question must be raised: is that what we intend by way of public policy? This is not some arbitrary budgetary consideration that will merely inconvenience a few people. Cutbacks of health research capabilities are short-sighted, ultimately very costly, and constitute a grievous disservice to millions of Americans whose health, well being, and quality of life depend on our government officials and scientists to respond.

SUMMARY RECOMMENDATIONS

We request that the implications presented in our comments be reflected in the narrative report. Improvement of mental retardation services depends on excellent basic behavioral and biological research on prevention, early diagnosis and intervention.

1. Increase funding to NICHD from $397,000,000 in the current fiscal year to $568,425,000. This is in contrast to the Administration request for $418,388,000 for fiscal year 1989. The amount we recommend will allow full NICHD funding of 810 competing research project grants.

2. Additional funds included to provide full-cost funding of the research centers, thereby eliminating negotiated reductions. Furthermore, the three

centers not funded under the FY 1989 administration request be restored and six new centers be established: four in learning disabilities as recommended in the report to Congress by the Interagency Committee on Learning Disabilities, and two additional centers on mental retardation allowing for the first expansion in 20 years.

3. Mandate that at least 25% of the extramural support of NICHD be for projects directly relevant to mental retardation, including an emphasis on prevention.

4. Congress express its commitment to the continuation of high-quality predoctoral and postdoctoral research training by appropriation funds in this category in the amount of $18,150,000.

5. An amount should be included in the NIH Building and Facilities appropriations for construction of Building 49, the combined NICHD, Neurosciences and Primate Building.

Trends in MR Funding*
(Millions of Dollars)

Year	Total CRMC Funds	Total CRMC-MR	MRDD	MRRC Core
1972	42,838,000	21,365,000	17,250,000	5,856,000
1973	41,971,000	21,330,000	16,642,000	6,533,000
1974	51,894,000	23,886,000	18,096,000	5,761,000
1975	55,094,000	25,420,000	18,884,000	5,672,000
1976	60,161,000	27,016,000	20,423,000	5,608,000
1977	64,979,000	28,419,000	21,434,000	6,166,000
1978	73,790,000	30,298,000	23,318,000	6,455,000
1979	102,492,000	35,321,000	28,121,000	6,759,000
1980	101,154,000	34,731,000	27,559,000	6,751,000
1981	106,055,000	32,997,000	26,969,000	6,623,000
1982	105,530,000	31,768,000	25,963,000	6,549,000
1983	123,346,000	35,270,000	29,306,000	7,343,000
1984	135,489,000	35,699,000	29,263,000	7,737,000
1985	157,727,000	44,329,000	36,365,000	9,298,000
1986	158,009,000	47,008,000	36,478,000	8,378,000
1987	190,505,000	54,066,000	42,726,000	9,224,000
Percents of Total CRMC				
1972		50	40	13.7
1973		51	40	15.6
1974		46	35	11.1
1975		46	34	10.3
1976		45	34	9.3
1977		44	33	9.4
1978		41	32	8.7
1979		34	27	7.0
1980		34	27	6.7
1981		31	25	6.2
1982		30	25	6.2
1983		29	24	6.0
1984		26	22	5.7
1985		28	23	5.9
1986		30	23	5.3
1987		28	22	4.8

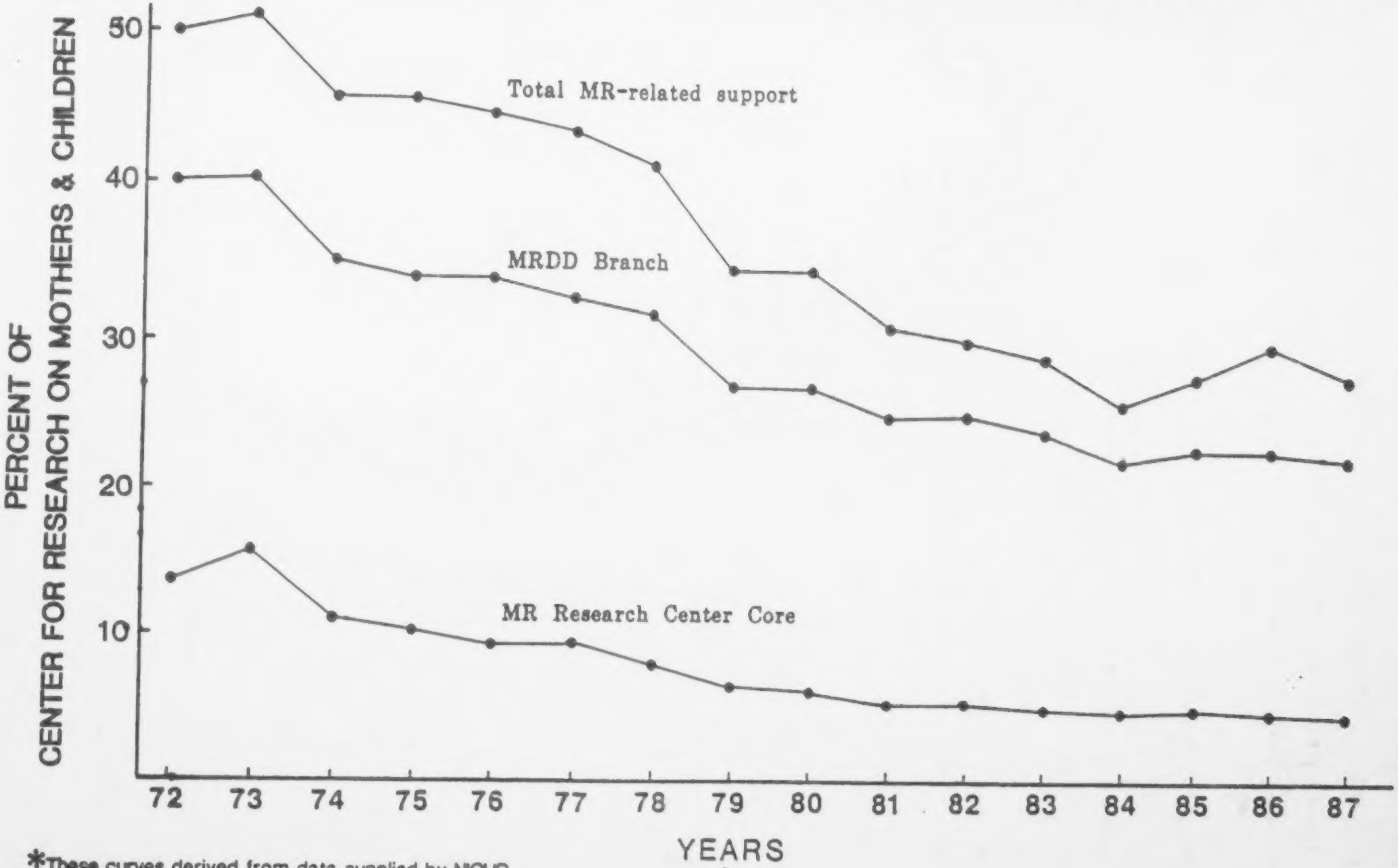
*Source of Data: NICHD, Office of Planning and Evaluation

CRMC = Center for Research on Mothers and Children MR = Mental Retardation research

MRDD = Mental Retardation Branch in the CRMC

MRRC Core = Mental Retardation Research Center (Public Law 88-164) core support

TRENDS IN SUPPORT OF MENTAL RETARDATION RESEARCH*



*These curves derived from data supplied by NICHD.

Senator CHILES. Thank you very much for your testimony, Doctor.

STATEMENT OF DR. CLAUDE J. MIGEON, PROFESSOR OF PEDIATRICS, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE, AND DIRECTOR, PEDIATRIC ENDOCRINE CLINIC, JOHNS HOPKINS HOSPITAL

Senator CHILES. Now we will hear from Dr. Claude Migeon, from the Pediatric Endocrine Clinic, Johns Hopkins University.

Doctor, I do not know whether I have pronounced your name right. I probably did not.

Dr. MIGEON. That is pretty good. Thank you. My name is Claude Migeon. I am the director of the Pediatric Endocrine Clinic at the Johns Hopkins Hospital, and I represent the Endocrine Society, an association of about 6,000 members who are interested in the study of hormones and treatment of hormonal disorders.

Because hormones play a major role in the control of many biological functions, disorder of their secretion has an enormous impact on health and medical costs. They result in abnormalities of sexual differentiation in infants, infertility of adults. Insulin dependent diabetes mellitus occurs in young children. Its complications appear in adulthood.

Osteoporosis results in bone fracture and takes an awesome toll on aging subjects. It must be noted that hormonal abnormalities are involved in many other problems, such as hypertension, some cancers, and some psychosis.

The endocrine studies and research is in part supported by NIDDK and also by the Reproduction Branch of the National Institute of Child Health and Human Development. It is also supported to variable degrees by other Institutes, including the Cancer Institute, the Heart-Lung, the Eye, Arthritis, and so on. This permits us to be somewhat less parochial about our demands and to support the overall budget and efforts of the NIH.

I think that for many years Congress has taken the lead in supporting biomedical research, recognizing that an investment would influence the progress of diagnosis and treatment of various conditions, and we certainly thank you for these efforts.

In summary, following our recommendation for fiscal year 1989 in research grants, we would like to point out that the percentage of grants awarded in relation to the total number of grants approved is no more than 25 percent.

It is clear that a great deal of biomedical advances are being lost when 70 to 75 percent of the approved grants are not funded. We would therefore urge you to try to attempt to increase the award rate to 40 or 50 percent.

In the research training program, the training of young individuals in research will remain our best long-term investment. Cuts in that area will result in loss of bright future investigators. The Endocrine Society recommends an increase of the number of trainees to 11,300.

In the area of equipment, very little funds have been earmarked for such purposes in the past 10 years. At the present time, biomedical research has been able to carry out its work in the old equipped and cramped quarters. However, it is clear that some work will be needed in this area.

In summary, we urge Congress to continue a strong medical program. We support a total NIH figure of $8.45 billion, as recommended by the ad hoc group for biomedical research. And I also would like to take this opportunity to thank you for permitting us to testify at this time. Thank you very much.

Senator CHILES. Thank you very much, Doctor. We appreciate your appearance and your testimony.

[The statement follows:]

STATEMENT OF DR. CLAUDE J. MIGEON

Introduction:

Mr. Chairman and Members of the Committee, thank you for giving me the opportunity to testify in support of NIH funding for FY '89. My name is Claude J. Migeon, Professor of Pediatrics, Johns Hopkins University School of Medicine and Director of the Pediatric Endocrine Clinic at the Johns Hopkins Hospital. I represent the Endocrine society, an association of about 6,000 members who are interested in the study of hormones and in the treatment of hormonal disorders.

Importance of Endocrinology:

Hormonal action in the body is basic to life itself. It is well known that hormones play a major role in reproduction: during fetal life, they control sexual differentiation; at adolescence, they bring about sexual maturation; during pregnancy, they are necessary for the maintenance of the fetus. Growth hormone and thyroid hormones permit normal development from infancy to adulthood. Parathyroid hormone and Vitamin D control bone and mineral metabolism. Adrenal hormones influence salt and water equilibrium which in turn influence blood pressure. Hormones of the pancreas regulate sugar metabolism and also lipid metabolism. Recent progress in Neuroendocrinology has shown that neurotransmitters are involved in behavior and brain function.

Just as importantly, the studies of hormones has markedly contributed to the increase of our knowledge of cell biology. Indeed, basic research in Endocrinology has brought new concepts of the modulation of the expression of genes. Genes provide the basic blueprint for life, but the control of their expression follows, in a large measure, the way hormones control the expression of their specific genes.

Endocrine Disorders:

Because hormones play a major role in the control of many biological functions, disorders of their secretion have an enormous impact on health and medical costs. They result in abnormalities of sexual differentiation of infants and adolescents, in infertility of adults. Insulin dependent diabetes mellitus occurs in young children and adolescents. Its complications appear in early adulthood. Osteoporosis resulting in bone fractures takes an awesome toll on aging subjects. It must be noted that hormonal abnormalities are involved in atherosclerosis, hypertension, certain cancers and some psychosis. The extent and diversity of endocrine or endocrine-related diseases demonstrate the need for further investigation in this field.

Sources of Support of Endocrine Research:

Endocrinologic research is in part supported by the National Institute of Diabetes and Digestive and Kidney Diseases and by the Reproduction Branch of the National Institute of Child Health and Human Development. It is also supported to variable degrees by all the other Institutes including the Cancer Institute, Heart-Lung Institute, Eye Institute, Arthritis Institute. This permits us to be less parochial than other areas of research and to support the overall efforts of NIH.

Recommendations:

For many years now, Congress has taken the lead in supporting biomedical research, recognizing that such investment would influence the progress of diagnosis and treatment of various conditions. Indeed, Congress realized that returns on the research investment is high both in dollars, by prevention or cure of diseases and in better health and well-being of the population. The members of the scientific community in general and those of the Endocrine Society want to thank Congress for its vision and wisdom in these matters. My remarks to this Committee today have the same purpose: to maintain the interest of Congress in providing appropriate resources for the continuation of the work of biomedical research.

a/ Research Grants: At NIH, the percentage of grants awarded in relation to the total number of grants approved by Study Sections, is less than 33%. A great deal of biomedical advances are being lost when 66% of the approved grants are not funded.

Statistics show that the total number of NIH grants has increased in the past 10 years. However, cuts in budget by peer reviewers as well as administrators, make it often necessary for investigators to apply for more than one grant. As a result, the number of individual investigators is decreased rather than increased. I urge you to fund a 40-50% award rate for approved research project grants while maintaining the current program balance among other research areas.

b/ Research Training: Training young individuals in research, remains our best long term investment. Cuts in that area will result in the loss of bright future investigators. Because it takes 5 to 7 years of apprenticeship, long range planning of research manpower must be done by investing training funds now. The Endocrine Society supports the recommendation of the Ad Hoc Coalition for Biomedical Research to increase the number of trainees at the NIH to 11,340.

c/ Equipment, Construction and Renovation: Very little funds have been earmarked for such purposes in the past 10 years. At the present time, the biomedical research has been able to carry on its work with the old equipment in cramped quarters. However, it is clear that we must start investing in this area. The Endocrine Society supports the recommendations of the Ad Hoc Coalition for Biomedical research to provide $250 million for construction, renovation and equipment in FY 1989.

In conclusion: We urge Congress to continue a strong medical program. We support a total NIH figure for FY '89 of 8.45 billion as recommended by the Ad Hoc Group for Biomedical Research Funding. This includes $250 million for facilities.

STATEMENT OF TERRENCE R. DOLAN, DIRECTOR, WAISMAN CENTER ON MENTAL RETARDATION AND HUMAN DEVELOPMENT, UNIVERSITY OF WISCONSIN-MADISON

Senator WEICKER [presiding]. The next witness, on behalf of the National Institute of Child Health and Human Development, is Terrence Dolan, the director of the Waisman Center on Mental Retardation and Human Development at the University of Wisconsin-Madison.

Mr. DOLAN. Senator, I appreciate this opportunity to appear today, and I would ask that my written testimony be put into the record.

Senator WEICKER. It will be.

Mr. DOLAN. I am director of the Waisman Center on Mental Retardation and Human Development at the University of Wisconsin-Madison.

It is one of the research centers, and one of a national network of research centers supported by the National Institute of Child Health and Human Development. I am appearing today on behalf of NICHD.

NICHD is the Institute that is given primary responsibility for the support of research on mental retardation and developmental disabilities at the NIH. And now is a particular exciting time in this field of science with tremendous progress.

For example, during the past year the anomalous gene and product of the gene responsible for Duchenne muscular dystrophy was identified at one of the mental retardation research centers, leading to a new opportunity to prevent that insidious disease.

However, the President's request for NICHD next year calls for a less than 1 percent increment increase in their budget, from $397 million to $399 million in non-AIDS funding.

This comes at a time when the NICHD is already near the bottom of the funding scale of the Institutes at the NIH. The award rate on approved grants at NIH is approximately 37 or 38 percent, with modest cuts in recommended budgets. At NICHD, the award rate is closer to 22 percent, with fairly major cuts in recommended budgets.

In addition, as Dr. Baumeister pointed out a moment ago, the proportion of funds going for support of research in mental retardation and developmental disabilities has reached an all-time low at the NIH.

And now, in the last couple of months, the Institute has announced that, because of the magnitude of the President's request, they are going to have to cut back on the number of research centers funded by the NICHD from 44 to 41.

We think this is tremendously short-sighted to cut back on the number of research centers. These centers were created by the Congress, and as I said, are making a tremendous contribution.

PREPARED STATEMENT

We urge the appropriations subcommittee to increase the NICHD budget by at least $15 million in order to prevent the cutting back on the number of research centers funded by that Institute, as well as to eliminate the tremendous budget cuts that are mandated at the present time. Again, I thank you for this opportunity to be here.

[The statement follows:]

STATEMENT OF TERRENCE R. DOLAN

Infants, School Age Children, Adolescents,Young adults, and those of us in middle and later years are at risk for a variety of serious psychological, behavioral, and health disorders. This is not news -- and no one better appreciates the magnitude and societal urgency of these problems than you do, as members of this committee. What is news is our vastly increased ability to tackle these problems directly, by applying breakthroughs in scientific technology and by utilizing new scientific frameworks resulting from a teamwork approach, one in which investigators from diverse backgrounds come together to study complex problems in an intensive and programmatic way.

The National Institute on Child Health and Human Development (NICHD) is our primary national resource for encouraging vigorous scientific inquiry into the central issues of human development, especially development gone awry. NICHD has a dual emphasis: (1) prevention and (2) effective treatment. At the heart of NICHD is a commitment to the study of basic biologic and developmental processes, including reproduction, growth, learning, intelligence, language, emotion, and social adaptation. What is so remarkable (NICHD's birth was only 26 years ago) is that discoveries about these basic processes have led to sweeping improvements in the health and well-being of children and families worldwide.

I am Dr. Terrence Dolan, Professor of Neurophysiology at the University of Wisconsin-Madison, and Director of the Waisman Center on Mental Retardation and Human Development. The Waisman Center is one of the 12 congressionally mandated NICHD Mental Retardation Research Centers -- a program established amidst great hope in 1963. On behalf of the national Mental Retardation Research Centers, with endorsement from the American Psychological Association, the American Academy on Mental Retardation, the American Association on Mental Retardation, and the Society for Research on Child Development, I am honored to present testimony on behalf of the NICHD.

The message I have to share with you today is this: we have entered a period of scientific promise that surpasses any we have experienced in this century. The opportunities for major advances in preventing mental retardation, and equally as important, for revolutionary understanding of how to improve the lives of mentally retarded and "at risk" children and their families are extraordinary. The critical resources, the scientific talent, and the commitment to conducting the rigorous and demanding research needed in this field are available. Without adequate and continuous funding for NICHD and its major programs, however, the achievements now possible will not be realized.

I recognize that almost all of us who present testimony here want dollars, usually more dollars, for our special interests. In this case, there are two real reasons why scientists throughout the country need more money to conduct scientific inquiry into our most urgent social and health problems. The first is that extraordinary technological breakthroughs have opened new fields of investigation. Accompanying these technological breakthroughs are dramatic increases in the cost of research. The second reason is that scientists now are probing questions about the most pervasive social and biobehavioral problems of our nation -- problems previously considered too complex and too political to subject to scientific investigation. The costs of conducting real-world research on these problems -- problems such as adolescent pregnancy, intergenerational cycles of poverty and marginal adaptation to society, child abuse and neglect, AIDS, low birthweight babies, use of contraception, patterns of parent-child communication, divorce and family stress, school dropout, learning disabilities, aggression, alcohol and drug abuse, mainstreaming and normalization of handicapped children, and deinstitutionalization and community adaptation -- are unavoidably very high and have risen faster than the inflation rate.

The increasing insights available as a result of technological and conceptual advances are accompanied, alas, by exponentially rising costs -- high costs that must be incurred if we hope to probe, in a more powerful way, the fundamental processes of development, as well to detect abnormalities never before detectable, and to monitor disease processes using methods that can elucidate mechanisms amenable to modification. The costs are attributable to many factors, from the straightforward ones of building, modifying, and maintaining equipment to the vital protection of the well-being of human subjects and the conduct of complex and highly sophisticated analyses of the information gathered.

Recognizing these escalating costs, NICHD has exerted systematic efforts to contain these costs, without jeopardizing science. The cost-containing efforts at NICHD include: (a) support for "common scientific core facilities" in interdisciplinary centers, so that scientists may share valuable equipment and the expertise of highly trained technicians; (b) sponsorship of working conferences where scientists share information and discoveries in a timely fashion, so that research already underway may benefit from breakthroughs elsewhere --

rather than operate in a mode that is highly competitive, non-communicative, and unnecessarily expensive; and (c) selective research training for outstanding and promising young investigators, frequently within the context of problem-focused research centers, such as the Mental Retardation Research Centers, the Population Research Centers, or team "program projects." This research training represents an extremely important function of NICHD, insuring that our new technology and new ways of thinking about developmental disorders will be "passed on." Continuity in commitment is essential within the scientific community if we hope to build a large knowledge base that will serve to inform physicians, teachers, nurses, caseworkers, therapists in the medical allied professions (such as speech therapy, physical therapy, occupational therapy), psychologists and psychiatrists, and parents themselves about "best practices." In fact, some of the "best practices" now in use -- ones that have dramatically improved the lives of handicapped children and their families -- have been built upon basic research conducted in NICHD research centers.

A good example of a recent and dramatic accomplishment at a Mental Retardation Research Center is the discovery of the gene that, when anomalous, is responsible for Duchenne muscular dystrophy and the gene by-product responsible for this terrible disorder. Because of the interdisciplinary collaborations of a team of scientists at an NICHD center, using the Center's shared core facilities, this significant discovery was made. This research, and other research using new recombinant technologies, is on the threshold of providing vitally needed interventions for genetic disorders.

Another set of important discoveries emerged while conducting long-term research in real-life settings. Investigators recognized that some of the "good" and "well-intentioned" social action programs (many created and funded by Congress) did not necessarily work -- that is, they did not necessarily cure or curb the problems they hoped to correct. This scientific research has extended beyond mere evaluation or judgement, however, and has sought to determine why programs (seemingly reasonable and well- motivated) do not work for certain people. I would like to mention two examples that have probed the "why's." The first example concerns prenatal care and a nutritional supplement to women during pregnancy. These may not be sufficient to counteract the negative consequences of dietary insufficiency prior to puberty or to offset the contribution of other social and intergenerational factors that alter pregnancy outcome. Instead, programs must be targeted to both men and women before conception, starting with children (parents of our future) who need consistent good nutrition and health care. The second example concerns the deinstitutionalization of individuals who are mentally retarded or mentally ill. We now know that the deinstitutionalization must be accompanied by opportunities for meaningful friendships (often in the form of "benefactors") and for personally rewarding activities, not just formal training programs or therapy. Otherwise, community living can be just as isolated, de-personalized, and impoverished as that in unacceptably inhumane and barren institutions.

NICHD is committed to problems such as these. Published results from studies on effective early intervention and prevention indicate that for every dollar we spend on prevention now, we avoid seven dollars in future care costs. That is, if we apply our knowledge and offer early services to children and families at risk for mental retardation, the return on invested dollars is sevenfold -- with decreases in special education placement, delinquency, welfare dependency, and employment (discounted for inflation) (Weikart, 1985). Disappointingly, of the vast sums we expend for services to persons with mental retardation, only 0.4 percent goes for research and training (Braddock, 1986).

We urge you to consider increasing the funding for NICHD to the level of $568 million recommended as the "best professional judgement" budget. However, recognizing the many requests before you and severe fiscal constraints, we wish particularly to emphasize that an increase of only $15 million above the administration's request for the NICHD would be sufficient to prevent the loss of three NICHD-supported research centers in the coming year. This $15 million increase also would permit restoring the severe 17 percent cutbacks that the NICHD centers have suffered in the past year. In addition, the $15 million would allow sufficient support to fund new centers, including those in the area of learning disabilities, as recommended to Congress. You have invested well in NICHD and the research centers over the past 20 years, but not at a rate comparable to that invested in other NIH programs. As you have heard in testimony today, the NICHD is near the bottom at the NIH relative to award rates at the other institutes (only the NIEHS and the NIANS have comparably low award rates). Further, we have reached an all time low in relative support for mental retardation and developmental disability research. We hope that you will act so that the opportunities for continued research and for improvement in the lives of citizens with developmental disabilities are not lost. Thank you for your attention.

Senator **Weicker**. Thank you very, very much, Mr. Dolan. I can assure you that we are going to do everything we can to restore some of the moneys. I do not know how successful it is going to be.

But I also agree with another matter which you alluded to, which is that the National Institute of Child Health and Human Development has been sort of the bottom of the Institutes as far as our regard is concerned.

And there are very obvious reasons for that. Most of the people that benefit do not vote. I am being very serious. It is not, in other words, where the political push comes from, and therefore it is so reflected.

And I can assure you that—I mean, I do not know if everybody read in the paper today where the catastrophic bill looks like it is going to come out. I am very proud of the Finance Committee. I am very glad that it is. I think we have needed the catastrophic health coverage for our older citizens.

During the debate on that 1 year ago I suggested that we amend it to include catastrophic care for children. That is even more catastrophic probably over the course of a lifetime, in terms of the child than it is an older person.

Believe me, the resistance was high, but I finally agreed that, as long as I could ascertain the costs, which I have the Institutes of Medicine right now in cooperation with the Carnegie Institute, that I could come back next year and I would be listened to.

I think we understand again the politics of that situation. There are a lot of older people, myself included, who vote. Kids do not. So there we have it. I do not think it reflects on us very well as a nation, insofar as our principles are concerned.

Because it used to be that this Nation lived for its children. Nothing reflects the negation of that principle more so than funding for the Institute itself or these matters as they arise.

So I can only say to you that I am very conscious of the correctness of what it is that you have presented before the committee, and I will do everything I can to assist in reversing that situation.

Mr. **Dolan**. Senator Weicker, I would be remiss if I did not thank you on behalf of many of my colleagues for your contributions.

You are really a champion for our interests, and we not only thank you but badly need your contribution, and we are happy to acknowledge that.

Senator **Weicker**. Thank you very much.

STATEMENT OF DR. MYRON GENEL, PROFESSOR OF PEDIATRICS AND ASSOCIATE DEAN FOR GOVERNMENT AND COMMUNITY AFFAIRS, YALE UNIVERSITY, ON BEHALF OF THE AMERICAN PEDIATRIC SOCIETY, THE SOCIETY FOR PEDIATRIC RESEARCH, AND THE ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRMEN

Senator **Weicker**. And next an old friend, Dr. Myron Genel, from Yale University. Dr. Genel?

Dr. **Genel**. Senator, as you know, I am Myron Genel. For the rest of the staff, I am professor of pediatrics and associate dean at the Yale School of Medicine.

At the outset, Senator, I want to commend you for your steadfast and continued support for biomedical research and for children's issues.

I represent the Public Policy Council. I am chairman of that group. The Public Policy Council represents three of the major academic pediatric societies in the United States. Our societies, which are listed in my formal testimony, represent pediatric investigators and the faculty and leadership of American medical school pediatric departments and research facilities.

Senator, I recognize the severe budgetary constraints under which you are obliged to operate in the appropriations process this year. I want to dispense with my more parochial pitch and instead emphasize from general principles, which I hope that you and your committee will be able to maintain in the difficult process of allocation of scarce resources which lie ahead.

First of all, our organizations fully support the recommendations of the ad hoc group for medical research funding, both for ADAMHA and for the NIH. And this is listed in my testimony.

Within this budget an attempt should be made to redress historical inequities that prevent Institutes such as NICHD from funding more than 22 to 25 percent of approved grants while other Institutes are able to fund in the range of 40 percent. Thus we support the recommendations of the Academy of Pediatrics for a large increase in funding for the NICHD.

Finally, we feel it is important to adequately support the provision of essentially communal resources and the infrastructure which is necessary to maintain our Nation's leadership in biomedical research.

PREPARED STATEMENT

In this category we would place support for the general clinical research centers, which are extremely important for pediatric research, especially for childhood AIDS, for the biomedical research support grants, which provide an almost critical source of fluid funds for our medical schools, for adequate training of physician scientists and for provision of adequate funds to permit clinical trials to go forward to translate these biomedical research advances into bedside care. Senator, I thank you.

[The statement follows:]

STATEMENT OF DR. MYRON GENEL

Mr. Chairman, I am Dr. Myron Genel, Professor of Pediatrics and Associate Dean for Government and Community Affairs at Yale University. I appear today representing the American Pediatric Society, the Association of Medical School Department Chairmen and the Society for Pediatric Research as chairman of their joint Public Policy Council. These organizations represent pediatric researchers, the faculty and leadership of all U.S. medical school pediatric departments and the faculty of medical and research facilities.

My testimony will focus on biomedical and behavioral research programs at the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA); the training of future scientists; and the education of new pediatricians.

RESEARCH AND RESEARCH TRAINING

To justify the future of pediatric biomedical and behavioral research is simple. One need only review the advances of the recent past. We can now control childhood diseases, which often result in life-long, disabling conditions, through safe and effective vaccines. We can control epilepsy; we can treat and manage diabetes and cystic fibrosis. We can save very ill and low birth weight infants. We can replace failing or diseased organs through transplantation. Our trauma and emergency centers can turn a life-threatening situation into a life-saving one.

However, we feel this is not enough. Instead of treating and managing diabetes, cystic fibrosis, cerebral palsy and sickle cell anemia, research could prevent the occurrence. The mystery of Sudden Infant Death Syndrome could be discovered. The possibilities through genetic engineering alone are impressive.

Members of this Committee and members of Congress have long recognized the value of biomedical research and the role the federal government must play. As pediatric researchers and educators we commend you on your continued support -- support which can be translated into medical benefits for today's and future children. It is now accepted that biomedical research, as with other basic research, requires a large-scale and long-term commitment which will allow scientists to explore the frontiers of medicine. While the private sector does have a role to play, the academic institutions and voluntary health organizations supporting biomedical research cannot carry the increasing financial burden. The federal government must continue to be the foundation for all aspects of biomedical research and training.

Increases for the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration over the past several years have been well used. In terms of real dollars, however, much more is needed. All the institutes are currently funding approved grants at a level lower than requested. Such a practice is not worthy of the NIH. As in any business endeavor, instability, both in finances and resources, can damage the outcome. Grantees do not know how much reduction they must accept from year to year, even though the grant has been approved for a set time span. A grantee cannot count on sufficient monies to pay the personnel involved or the expenses incurred. A related but separate issue is the number of grants funded by each institute. Some institutes fund as high as 40 percent of the approved grants; some, NICHD in particular, fund as low as 25 percent. High quality research projects are having to search for funding through private sources or delayed until funding can be secured.

Another new problem has arisen. As some of the research passes into the clinical trial stage, new funds are needed for the contracts to do these trials. These trials are necessary before what is learned can be used in health care. However, the funding available for contracts is limited. To have solutions available and not complete the process seems short-sighted.

For pediatrics, the General Clinical Research Centers program within the Division of Research Resources continues to be an important component of research. These provide the promise of direct benefit to infants and children and are one of the major sites for the study and treatment of pediatric AIDS. In some cases, these centers are the best source of care available. They also provide a training ground for new investigators.

Provision for the training of new physician scientists, both through individual and institutional support, is critical. Physicians are needed to provide patient management whenever pediatric patients are being used in a research program. These investigators must interpret what is learned and translate this knowledge to the practice setting. In recent years, despite cooperative agreements between NIH and public entities, such as the model established between the National Institute for Child Health and Human Development, the Association of Medical School Pediatric Department Chairmen and the American Academy of Pediatrics, funding for training of these scientists has declined. In a training program that can last from five to seven years, variances in training funds can have a severe effect. We urge this Committee to support increased funding of research training for physician scientists.

We are all aware of the need to find a way to control and prevent the spread of AIDS. Pediatrics is not unaffected by this dread disease. Monies to fund AIDS research, manpower resources to do the research and treat the disease, and delivery of the needed services are all a drain on the health care system and the biomedical research system. We applaud Congress' desire to address this problem by allocating funds directly to AIDS treatment and research. Congress must also be aware of how such a disease can cause a diversion of resources from other areas. There may be no answer to this dilemma, but we cannot allow children to be deprived of improved medical technology, treatment and prevention.

Last year, the Ad Hoc Group for Medical Research Funding proposed a five-year plan to build a biomedical and behavioral research capability which would enhance the development of future projects and ensure the availability of scientists to participate in such research The aim of such a plan is still viable. This plan also stresses all the activities of the NIH, not solely the new, competing and obligated grants. It also emphasizes the need to provide for the clinical research centers, the training, and other critical programs within NIH. We support the Ad Hoc Group for Medical Research Funding in its recommendation of $8.221 billion for NIH.

In addition, we support the proposal from the Ad Hoc Group that seed money be provided which would stimulate institutions to revitalize and renovate the research facilities. We recommend $250 million for this necessary expenditure to renew facilities.

Research and research training through ADAMHA should not be ignored.

Substance abuse continues to be a problem which affects all facets of our society, as well as being a significant factor in the spread of AIDS to women and children. Research opportunities within this field should be encouraged. Therefore, we support the Ad Hoc Group for Medical Research Funding in its recommendation of $716 million for research and training at ADAMHA.

PRIMARY CARE TRAINING

In addition to training a cadre of physician scientists, a goal of pediatric residency training programs is to produce physicians capable of providing primary health care for infants, children and adolescents, performing as advocates for that population and counseling their families. Each of these functions is critical for today's pediatrician and they constitute a complex set of responsibilities. Pediatricians are expected to manage both acute and chronic health problems and help care for children with emotional disturbances and disabling conditions.

To meet these needs, ambulatory and other non-traditional training sites are of value. However, funding for such training programs is not as readily available as for in-hospital residency programs. Current payment sources, whether from direct payment by the patient or through third-party reimbursement, cannot cover the costs of such non-traditional sites. Federal support, currently through the Title VII Primary Care Training Grants, for the training of pediatricians must be continued.

This year there were a number of approved grants for the general pediatrics/general internal medicine program which were unable to be funded. In light of studies which have proved the merit of such financial support for these residency programs, we recommend funding this program at $22 million.

Senator **Weicker**. Tell me, in an effort to assist me as I speak around the countryside, give me a practical response to this question, a response which could be understood by the guy on the street.

How do the National Institute of Child Health and Human Development activities relate to young kids in New Haven, CT? In other words, I think it is very difficult to make a connection with the activities going on in this Institute for the children of Washington, DC, vis-a-vis the common, day-to-day ailments and problems of my child in New Haven, CT. What do they do there that affects children in New Haven, CT?

Dr. **Genel**. Everything they do affects children in New Haven, CT, from the standpoint of——

Senator **Weicker**. Why are you, Mike Genel, at Yale University, not adequate to the task of helping these kids? And the National Institute of Child Health, what do they add to the solution?

Dr. **Genel**. I think some of the most critical issues that affect our understanding of normal development, normal development processes, how normal children grow, and deviations from normal, take place through the National Institute of Child Health and Development.

I think our understanding of the events that lead to some of the most profound problems that people have to face, birth defects, arise from research that is being done at the National Institute of Child Health and Development.

The best means of preventing these dreadful occurrences lies through better understanding of the embryological process, the process of gestation. This is the research that is being done at the National Institute of Child Health and Development. I think our greatest opportunity for prevention of birth defects lies in greater understanding and prevention through support of NICHD.

As you have heard from the previous witness, I think the treatment and understanding of the profound developmental effects that occur and our best response lies through support of that type of research.

I think you put it very eloquently. Our constituency does not vote. And I think perhaps those of us who are their advocates have been a little bit too reticent to speak out.

Senator **Weicker**. Let me ask you another question which borders a little bit more on the controversial, although in my mind it does not. I think it is really misinterpretation of the terms.

How is it possible to understand problems of young people or those actually in a mother's womb without fetal research? I am not getting into the fetal tissue issue, I am just saying fetal research. How is it possible to scientifically help our children without a knowledge of that?

Dr. **Genel**. Well, Senator, I have been struggling with that for a number of years, and I really do not know how it is possible. I suspect some would like us to use astrologers.

Senator **Weicker**. I mean, I think that for some reason or other people feel research is somehow just a matter of inducing abortions and then using the fetus, blah, blah, blah.

I do not know how you go ahead and help me at my age, unless there is active research done on living people, in other words, of my age to help me with whatever my problems happen to be. And certainly that has to take place also insofar as fetuses and the newborn are concerned. Otherwise you condemn them to the past.

Dr. GENEL. Absolutely. And some of the most incredible advances that have occurred during the last decade in terms of our understanding of fetal development have come through very judicious and very careful research that is directed to understanding the fetus and fetal development.

Senator WEICKER. Well, I want you to know that I was asked on the NIH reauthorization, which as you know was passed out of committee, if I am not mistaken, but has not been brought to the floor of the Senate, and the reason is that there are certain Senators saying that, if we do not renew the ban on fetal research, they will filibuster the bill.

On the other hand, if we will agree to the ban, and actually extend it for 3 years, why then they will let the bill for NIH reauthorization go through. And would i agree to that? And I said no, I would not agree to that.

I think we have had enough of this nonsense on the floor. And I might add, I am not talking prolife or prochoice or anything like that. I am talking the cause of science, giving the best chance for our people to be born, to grow, to live.

I have seen this issue here. Obviously the fetal tissue issue. We saw where for 1 year, it was 2 years that Senator Chiles and I asked for a mailer to go out from the Centers for Disease Control on AIDS. Right? Am I correct?

Two years. Senator Chiles' initiative, 2 years ago. That should have been done in 1 year, it could have been done in 1 year, except the philosophers got in there. So a whole year was lost on that mailer.

Now, let us understand, I think you as a physician would say, certainly within that 1 year people contracted AIDS or died from it that would not have been the case, if you will, had they had information in hand a year earlier.

What was the other matter that, there was another matter in this—we have a variety of these situations cropping up in the name of philosophy rather than the name of science that are devastating to medical science. That field which we excel at in the United States, and which promises life.

My God, you talk about prolife, that is what the National Institutes of Health and you guys are all about. And to sit there and tie one hand behind your back, I think that is criminal. That is condemning people to death, or to a quality of life that is just short of death.

I am going to say no. I might go down the chute on these issues, but I think it is clear that the American people have to understand there is a price to be paid for this philosophical meandering in and out of the scientific community. There is a price to be paid.

Dr. GENEL. I absolutely agree with you. And Senator, I think you have put this more eloquently than any of us can do in the biomedical research community.

None of us have asked for unbridled permission to do fetal research. What we have asked for is to be able to maintain and continue to do fetal research under appropriate restraints and constraints.

There are mechanisms that were put in place years ago that have never been employed. So that research that was of any question, but might have social value, could be evaluated properly by an appropriate mechanism.

I think that is all that any of us really suggest should happen. There should be a mechanism for which a judgment can be made as to the relative value versus the risk. We do not have that at this point.

Senator WEICKER. Well, I know you do great work for the children of, not just my State, but the Nation. And I thank you very much and thank you for your testimony.

Dr. GENEL. Thank you, Senator.

STATEMENT OF HELENE GRUBER, PRESIDENT, ASSOCIATION FOR CHILDREN AND ADULTS WITH LEARNING DISABILITIES

Senator WEICKER. Our next witness is Helene Gruber, president of ACLD.

Ms. GRUBER. Good morning, Senator Weicker. I am Helene Gruber, president of the Association for Children and Adults with Learning Disabilities.

ACLD is a 60,000-member organization comprised of parents and family members of individuals who have learning disabilities, interested professionals who work with our children, as well as adults and youth who themselves have learning disabilities.

We are extremely grateful as an organization and as parents for the efforts you, the chairman, and the other committee members have made to continue to ensure adequate funding for programs for the handicapped, including the learning disabled.

As always, we are hopeful that we will see an increase in the Education for All Handicapped Act funding. We believe an increase of $245 million would do much to move the Federal Government toward meeting the funding level pledge that is now 10 years overdue.

We are also anxious to see increases in specific new initiatives under the act, including the early intervention program and the mandated level for the preschool program.

We, of course, also support the maximum increase your subcommittee will allow for rehabilitative services, vocational education, job training, and other programs serving the handicapped.

This year I want to make a special appeal to the subcommittee to provide funding for what was identified in the NIH section of your committee report last year as the learning disabilities initiative.

Thank you for that report language, which was extremely prompt and a timely followup to the 1987 report to Congress of the Interagency Committee on Learning Disabilities. That report made the sobering estimate that 10 percent of the population of this country suffers from learning disabilities. That is 240 million Americans.

The report recommended continuing research for four Institutes of NIH, four new interdisciplinary research centers to be initiated by NICHD, a research clearinghouse, and grants to train future researchers.

Since the report was not forwarded to Congress until August 1987, it was not included in 1988 funding, nor was it included in the administration's recommendations for 1989. But your language, sir, thank you, caused NICHD to move ahead with requests for applications for the four new research centers and in positive actions by several other agencies. Now what we need is the appropriations to continue those implementations.

To fully fund the learning disabilities initiative will require $7.25 million. While we recognize that funding is difficult, we think this is really a small investment in the future of 24 million Americans.

PREPARED STATEMENT

We hope that your committee will take every effort, sir, to fully fund the program. When you look at the fiscal and social ramifications of learning disabilities for this number of Americans, we hope that we can find money for this research. Thank you.

Senator WEICKER. Helene, thank you very much for your testimony. It is greatly appreciated. Thank you for making an effort to be here.

[The statement follows:]

STATEMENT OF HELENE GRUBER

Mr. Chairman, I am Helene Gruber, President of the Association for Children and Adults with Learning Disabilities. ACLD is a 60,000 member organization including the parents and family members of the learning disabled, interested professionals who help our children, and youth and adults who are themselves learning disabled. We have testified before your Committee in the past and we appreciate the opportunity to do so again this year.

We are extremely grateful, as an organization and as parents, for the effort that you and the Ranking Member of the Committee and the other Committee Members have made and continue to make to ensure adequate funding for programs serving the handicapped and the learning disabled. As always, we are very hopeful that we will see an increase in the Education for All Handicapped Act funding. We believe an increase of $245 million would do much to move the federal government toward meeting the funding level pledge that is now ten years over due. We are also anxious to see increases in specific new initiatives under the Act including the early intervention program and the mandated level for the pre-school program. We, of course, also support the maximum increases your Sub-committee ceiling will permit for Rehabilitative Services, Vocational Education, Job Training and other programs serving the handicapped.

This year, I want to make a special appeal to provide funding for what was identified in the NIH Section of your Committee Report last year as the "Learning Disabilities Initiative". We want to thank you and the Ranking Member for that report language which was an extremely prompt and timely follow-up to the 1987 Report to Congress of the Interagency Committee on Learning Disabilities. That Report made the sobering estimate that 10% of our population - fully twenty-four million Americans - are likely to be suffering from specific learning disabilities. The Report recommended continuing research at four Institutes of NIH, four new interdisciplinary research centers to be initiated by NICHD, a research clearinghouse, and grants to train future researchers. Since the Report was not forwarded to Congress until August, 1987, it had no affect upon FY'88 funding decisions nor on the Administration's request for FY'89 - which had already left NIH. But your report language, based upon the Draft

Report, has resulted in NICHD moving ahead with Requests for Applications for the four new research centers and in positive actions by several other agencies. These agencies now require additional appropriations to proceed with implementation of the Report.

To fully fund the Learning Disabilities Initiative in FY'89 - including the continued research,interdisciplinary research centers, research clearinghouse, and research training - will require $7,250,000. While we recognize that any new funding is difficult to initiate these days, it does seem like an extremely small price to pay for research that could improve the lives and productivity of perhaps twenty-four million Americans. Imagine, for instance, that such research results in a clear understanding of brain dysfunctions that are found to cause several specific learning disabilities. Treatments that remedy or modify these disabilities may follow-on soon after. Then we begin to see, in just a few years, a change in the number of youngsters who under-achieve or drop-out of school, a reduction in juvenile delinquency, a lowering of welfare dependency, greater success in our job and skill training programs. You see, when we talk about a disability that affects twenty-four million Americans, the social and fiscal consequences of research that can remedy or modify the disability can be very significant. So I am asking you to do your best - and I know you will - to find new money for this research. If we must prioritize, we will choose the research centers first. But I hope you can find a way to implement all of the major recommendations of the Report.

Once again, I want to thank you for your time, your attention to our concerns and your support for learning disabled children and adults.

STATEMENT OF DR. HARRIET B. PRESSER, PRESIDENT-ELECT, THE POPULATION ASSOCIATION OF AMERICA

Senator WEICKER. Our next witness is Harriet Presser, president-elect of the Population Association of America.

Dr. PRESSER. Senator, my name is Harriet B. Presser. I am president-elect of the Population Association of America and professor of sociology at the University of Maryland, College Park. I appreciate the opportunity to speak to you today, both on behalf of NICHD and the National Institute of Aging, NIA.

I am here today on behalf of the Population Association of America, the professional research society of some 2,700 demographers, economists, geographers, and sociologists. Indeed, PAA represents nearly all those involved in scientific research on population and demography.

While PAA members receive support from many sources, an important funding source for demographic research comes from NIH, particularly through the Center for Population Research at NICHD and the National Institute of Aging.

The demographic research supported by NIH is focused on critical issues of health policy, such as adolescent fertility, AIDS research, and the so-called oldest old, those 85 and over.

The Demographic and Behavioral Science Branch at NICHD supports a wide range of studies on the growth and distribution of our population in relation to individual and societal welfare.

Today I would like to highlight just one area, AIDS research. This major research effort is illustrative for several reasons. It demonstrates how the established demographic research capability at the Institute can be directed promptly to key research dimensions of this new public health crisis and how it complements the ongoing biomedical research program.

There is consensus that efforts to stop the spread of the AIDS virus will depend on a better understanding of sexual behavior. However, there is a scarcity of current data on the subject.

Alfred Kinsey's pioneering research program conducted over 40 years ago continues to be widely referenced and used as a basis of current assumptions regarding behavior, even though it is seriously outdated.

The AIDS public health emergency has made the need for new data critical, and NICHD's Demographic and Behavioral Science Branch has been designated to coordinate this groundbreaking research.

Two projects are currently underway. One on adolescents and the other on adults. These projects will provide the most current and representative data which will serve as a critical denominator for future research efforts.

Congress increased by $30 million the appropriation for NICHD in fiscal year 1988. In spite of this increase, the Institute was forced to make reductions in the number of competing grants. This was due to the fact that the increasing cost of an average grant rose by 14 percent. It was also forced to reduce funding in its centers by 17 percent.

As previously mentioned, the current budget levels at NICHD can only fund approximately one-fourth of their approved projects, which is well below the NIH average of one-third.

For fiscal year 1989, the President has requested $418 million for NICHD, which includes about $30 million for AIDS. This inadequate increase would have grave consequences for NICHD. The funding rate would drop to 23 percent. The number of competing grants would decrease to 449, and three research centers would have to be eliminated.

The Population Association of America urges this subcommittee to continue its commitment to quality research at NICHD and support an appropriations level of $568.4 million.

Another important source of demographic research comes from NIA. Demographic research on aging is an emerging and expanding field. A major initiative is on the relationship of health to longevity.

Another focus is the so-called oldest old, those age 85 or more. Although this is the fastest growing segment in our population, we still do not know very much about the group.

For fiscal year 1989, the President had requested $204 million for the Institute. This level would require the elimination of one center and reduce the number of competing grants from 209 to 177.

We urge the subcommittee to support an additional increase for fiscal year 1989 and raise the appropriation to $281 million. This level would allow NIA to fully fund 37 percent of approved projects and enable the National Institute on Aging to continue a broad spectrum of research, including funding for the oldest old initiative, planning and developing appropriate plans for long-term care, a new survey on retirement and health issues, and a longitudinal study on aging.

PREPARED STATEMENT

In summary, we believe that the amount of $568.4 million for NICHD and $281 million for NIA are amply justified, and we respectfully urge you to consider increased funding in the appropriation process. Thank you.

Senator WEICKER. Thank you very much for your testimony. I greatly appreciate it. Thank you very much.

[The statement follows:]

STATEMENT OF DR. HARRIET B. PRESSER

Mr. Chairman and Members of the Subcommittee on Labor, Health and Human Services and Education of the Senate Appropriations Committee, my name is Dr. Harriet B. Presser. I am President - Elect of the Population Association of America and Professor of Sociology at the University of Maryland, College Park. I appreciate the opportunity to speak to you today regarding the appropriations for the National Institute For Child Health and Human Development (NICHD) and the National Institute on Aging (NIA) at the National Institutes of Health (NIH). Your interest and support for the National Institutes of Health in times of budget constraints have enabled this institution to maintain its preeminence in the scientific research arena.

I appear before you today on behalf of the Population Association of America (PAA), the professional research society of some 2,700 demographers, economists, geographers and sociologists. Indeed, PAA represents nearly all those involved in scientific research on population and demography. While PAA members receive support from many sources, an important funding source for demographic research comes from NIH, particularly through the Center for Population Research at NICHD and from The National Institute on Aging. The demographic research supported by NIH is focused on critical issues of health policy, such as adolescent pregnancy, AIDS research and the so-called "oldest old."

The Demographic and Behavioral Science Branch at NICHD's Center for Population Research supports a wide range of research on the growth and distribution of our population in relation to individual and societal welfare. For example, recent research on child care has provided the critical baseline data for policymakers on the use and anticipated demand for child care services. Today I would like to highlight one area -- AIDS research at the Demographic and Behavioral Sciences Branch at NICHD. This major research effort is illustrative for several reasons: it demonstrates how the established demographic research capability at the Institute can be directed promptly to key research dimensions of this new public health crisis and how it complements the on-going biomedical research program.

As you know, it is unlikely that a fully effective medical treatment or vaccine for AIDS will become available in the near future. For this reason, there is consensus that efforts to halt the spread of the human immunodeficiency virus (HIV) will rely on preventive efforts. These efforts will depend on an understanding of behavior as it relates to sexual activity. On this subject, there is a scarcity of current data. Alfred Kinsey's pioneering research program conducted over forty years ago continues to be widely referenced and used as the basis for current assumptions regarding behavior.

With the emergence of the AIDS public health emergency, the need for new data has become critical, and the Demographic and Behavioral Science Branch (DBSB) at NICHD was seen as the logical unit to coordinate this groundbreaking research. The Branch has been able to respond quickly because of its relationship to researchers who are skilled at designing surveys dealing with sensitive questions.

One project to design a representative and current survey of adult sexual behavior in the United States has already been approved. A major focus of this survey will be sexual behavior and other risk taking behaviors as they relate to sexually transmitted diseases, particularly AIDS, and contraceptive use. Another study currently being designed is focused on adolescents. In order to understand adolescent sexual and contraceptive behavior, we have to understand how teenagers are influenced by their families, friends, schools, religious institutions, and the general nature of the communities in which they live. Both these studies will make major contributions to AIDS prevention efforts, and will provide the most current and representative data. This data will also serve as the critical denominator for future research efforts.

For Fiscal Year 1988, Congress increased the appropriation for NICHD from $367 million to $397 million for Fiscal Year 1988. In spite of this increase, the Institute was forced to make reductions in the number of competing grants awarded. This was due to the increasing costs of grants. For fiscal year 1988, the average competing grant rose 14 percent from 1987 levels (from $143,000 to $163,500) and the cost of the average non-competing grant increased $6,700 (from $156,500 to $163,200). NICHD was also forced to reduce funding to its Centers by 17 percent. At current budget levels NICHD can only fund approximately 26.6 percent of their approved projects. This is well below the NIH average of 33.8 percent.

For FY 1989, the President has requested $418 million for NICHD. This level would have devastating consequences for NICHD: the funding rate would drop to 23 percent; the number of competing grants would decrease from 468 - 449; and three research centers would have to be eliminated. Existing programs would also be cut: competing grants by 17 percent and Centers by 16 percent.

The Population Association of America urges this Subcommittee to continue its commitment to quality research at NICHD and support an appropriations level of $568.4 million. This amount would put NICHD's award rate at the 40 percent level--the higher end of the award rates at NIH; would maintain funding for Centers; and enable the Institute to continue all facets of its research program at full cost.

Another important source of demographic research comes from the National Institute on Aging (NIA). Demographic research in this field is an emerging and expanding field. Only a decade ago the role of demographers in aging was largely descriptive, documenting the dramatic increases in the number of elderly. Recently the techniques of demography have been brought to bear in a more analytic fashion. The outcome of such efforts has produced new insights into the links between mortality improvements and changes in disability and morbidity linkages, and more reliable projections of service demands. New research efforts have helped to shift the policy and planning debate away from chronological age per se to examination of other factors related to the aging process. The major responsibility for stimulating and funding research in this area is at NIA's Behavioral and Social Science Cluster.

A major initiative underway at the National Institutes on Aging is research on the relationship of health to longevity. What does increased longevity mean for active life expectancy in terms of disability and long-term care, community and social services and economic and employment needs? Another focus at the National Institute of Aging is the so-called "oldest old," those age 85 or more. Although this is the fastest growing segment in our population, we still do not know much about the group. We need better information on actual health expenses of people in this age group as they grow older (longitudinal data) if we are to be able to better forecast life expectancy and disability expenses. Such information is essential for planning and developing appropriate plans for long term care.

For FY '89 the President has requested $204 million for the Institute. This level would require the elimination of one Center and reduce the number of competing grants from 209 to 177. We urge this Subcommittee to support an additional increase for Fiscal Year 1989 and raise the appropriation to $281 million. This level would allow NIA to fund fully 37 percent of approved projects and enable the National Institute on Aging to continue a broad spectrum of research including: funding for the" oldest-old" initiative; planning and developing appropriate plans for long term care; a new survey on retirement and health issues; and a longitudinal study on aging.

In summary, Mr. Chairman, we believe that the amount of $568.4 million for NICHD and $281 million for NIA are amply justified, and we respectfully urge you to consider increased funding for NICHD and NIA in the appropriation process.

STATEMENT OF DR. BERNARD WEISS, ENVIRONMENTAL HEALTH SCIENCES CENTER, UNIVERSITY OF ROCHESTER, SCHOOL OF MEDICINE AND DENTISTRY

Senator **Weicker**. Next witness, Dr. Bernard Weiss, of the University of Rochester. Dr. Weiss?

Dr. **Weiss**. Senator Weicker, thank you for the opportunity to appear before this committee.

I am here to speak for the Association of University-based Environmental Health Science Centers. I am professor of toxicology and deputy director of the center at the University of Rochester.

The association represents 15 research centers in various parts of the United States. Together with NIEHS, we are linked into a network that is equipped to attack big and complicated problems.

Let me give you an example of a big and complicated problem. The environmental causes of disease. We have become aware that Parkinson's disease and some aspects of Alzheimer's may be traced to environmental causes.

You have talked about costs and benefits earlier today. Let me give you another example of costs and benefits. If, as a result of this research, we can delay the entry of 30 patients by 1 year into nursing homes for degenerative disease, we will have saved $1 million.

The centers have suffered under a cap for the past 4 years, which means that our resources are no longer adequate to deal with these big and complicated problems. An addition of $1 million to the center budget would help us restore the scientific expertise that we contribute to this society.

We have many young scientists who are eager to ride the crest of all these new developments in science. We urge you to support the centers.

Senator **Weicker**. Do we have your full statement as a part of the record, Dr. Weiss?

Dr. **Weiss**. Yes, you do.

Senator **Weicker**. I very much appreciate it. Thank you very much.

[The statement follows:]

STATEMENT OF DR. BERNARD WEISS

Mr. Chairman, committee members. My name is Bernard Weiss and I am here to speak for the Association of University-based Environmental Health Sciences Centers. I am Professor of Toxicology and Deputy Director of the Center at the University of Rochester School of Medicine and Dentistry.

The Association represents 15 research centers, supported by NIEHS, that are based at universities in all parts of the U.S. Ten are devoted directly to health research; five marine and freshwater centers conduct research on aquatic organisms in the context of health issues. The biomedical centers are located at Harvard University, New York University, Johns Hopkins University, Mt. Sinai School of Medicine, Vanderbilt University, University of Rochester, Oregon State University at Corvallis, University of California at Berkeley, MIT, and the University of Cincinnati. The marine/freshwater centers are located at Duke University, University of Washington, Medical College of Wisconsin, Oregon State University, and the Mt. Desert Biological Laboratory in Maine.

Centers serve a special function in environmental health research. Few environmental health issues can be resolved by individual scientists or even individual disciplines working in isolation. Centers nurture breadth. Their faculty come from many different disciplines, including branches of clinical medicine; they provide core facilities and resources beyond the reach of most individual researchers; and they offer a setting for attacking big and complicated problems.

Centers continue to grow in visibility and responsibility because public anxieties are expanding, not receding. One example of this concern is Proposition 65 in California, which mandates labeling of potential sources of alleged carcinogens and reproductive toxicants. Other states are considering similar regulations. Without a foundation of scientific data to generate public confidence, it is almost inevitable that voters and governments will select the most extreme risk estimates and impose the most stringent controls possible on chemicals. It can be a costly strategy, not just for business, but for the community, because it invariably distorts our priorities. For example, without data confirming the negligible mercury exposure from teeth filled with amalgam, we might have embarked on a disastrous 60 billion dollar fad in dental care.

Such anxieties also foster reluctance to adopt new technologies. Many communities will soon be forced to turn to methods of waste disposal other than landfills. Incineration and other alternative technologies are options opposed by groups who fear their unfamiliar products. Without a scientific grasp of the risks posed by such products, which is the first step in health protection and in public confidence, we face a harrowing disposal crisis in a dismayingly short time.

Proposition 65 is aimed mostly at cancer. But we face many more environmental health threats than cancer. Preliminary findings at Rochester suggest a connection between multiple sclerosis, an immune system disorder, and excessive zinc exposure. This finding becomes even more intriguing given a recent report indicating that a protein encoded by the AIDS virus binds zinc in a distinctive molecular structure. The biological roles of metals are among the most intensively studied areas in our centers because metals influence processes as diverse as fetal brain development and lung cancer.

We are also becoming alert to the possible connections between environmental chemicals and degenerative diseases, especially those affecting the nervous system. A small epidemic of Parkinson's Disease in California, traced to a constituent of illicitly manufactured drugs, has sparked a search for potential contaminants in the environment that might help explain the origins of this affliction. New data from the Western Pacific now suggest that a form of Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease), often accompanied by a dementia similar to Alzheimer's Disease, arises from ingestion of a substance found in certain plants consumed as foods.

I suspect that we will be finding further connections between such diseases and specific chemicals in our environment. Even if we identify no more than a small contribution, consider the costs and the benefits. If only 30 patients, on the basis of such knowledge, can delay nursing home care for just one year, we will have saved about one million dollars.

Some outcomes are more subtle than disease. New research now shows that maternal exposure to lead at levels that, in the past, we had considered low or moderate, reduces scores on tests of infant development. Experimental data in animals affirm these conclusions. If we project the implications of these findings, we see that such modest exposures can sharply limit the number of individuals with unusual intellectual potential. In an era of intense international competition for scientific and technological dominance, could such limits drag us into a national calamity? Fortunately, helped by contributions from our centers, we now understand much more about lead toxicity and can take the steps to prevent it.

NIEHS had the vision to develop and guide our network of centers. The investment has paid immense dividends. We now have in place a cadre of scientists whose interests and efforts coincide with public concerns about the hazards of environmental toxicants, whose stature and knowledge serve nearly all federal and international efforts in toxicology, who are available as community resources, and who are training young investigators riding the crest of exciting new advances in the life sciences.

Legislators and scientists both learn to cherish stability. Like you, we spend much of our time campaigning (in our case, for research support), but we also must provide much of the accessory support, such as our own salaries, salaries for staff members, even telephone service. Center funds help foster a bit of stability in this competitive life. The cap on individual center budgets, however, means that they provide less and less stability each year, so we must spend more and more time campaigning. The costs of research can be expected to rise with the cost of living, along with the investments required to install and maintain modern laboratory equipment and new technologies. The addition of only one million dollars to the NIEHS budget request for centers will help arrest the erosion of their resources that has taken place during the past few years and allow them to keep pace with these accelerating demands.

Younger faculty and graduate students find this process daunting and depressing, especially when a green MBA may earn as much as an established professor. They, especially, are eager to get on with the challenges that, by your own past actions, you have encouraged them to pursue. I urge you to continue to nurture this unique program of American biomedical science.

STATEMENT OF JOHN M. CORNMAN, EXECUTIVE DIRECTOR, THE GERONTOLOGICAL SOCIETY OF AMERICA

Senator WEICKER. Next witness is John Cornman, executive director of the Gerontological Society of America.

Mr. CORNMAN. Good morning. Thank you for having us here.

If I may, before I start my brief comments, note gently in passing that, even though older people vote, NIA has one of the three lowest funding rates of peer reviewed grants of any of the Institutions. I will just state that for the record.

Senator WEICKER. Well, I would agree with you. I have to say that, as you know Mr. Cornman, I have tried to achieve moneys for training for health professionals in the area of geriatrics. The Alzheimer's centers, I believe, are ones that were initiated by this Senator when he was chairman.

And let me say this to you right now. I do not think that we are spending the money that we should on the National Institute of Aging in the sense of meeting, relating to the statistics that are coming over the Hill.

To me the matter of kids is a matter of principle. You know, that is the stuff that we are supposed to generate inside. The matter of the aging in this country, you know, principle aside, that is just plain a matter of numbers.

The over-85 age population will double by the year 2000. Am I correct? The over-65 will double by somewhere between 2010 and 2020, somewhere in that period of time? Will double. And we do not have the health professionals to go ahead and deal with it.

So I think it is great that everybody is picking up a Social Security check. But I do not think it does much good if you are not well. And I could not agree with you more. I think your budget, the budget that you speak for, also is too low. Much too low.

But tell me this. How many of the elderly of this Nation will complain about the inadequacy of the NIA budget as compared to those who will complain about COLA's? Nobody is going to think about NIA. And it is their own quality of life that is involved.

Mr. CORNMAN. I would second that. I am also disturbed that many older groups do not complain about the low level of funding for educating our young people, because if you are concerned about the future of programs for the elderly we need a very productive work force and we need well-educated younger people. And I think that is an elderly issue. And I am very disturbed that sometimes people who speak for the elderly do not have a broad enough basis.

If I might I would just like to stress, you do have my comments—

Senator WEICKER. Do not worry about the time. I took some of your time.

Mr. CORNMAN. I would like to stress just one point, and that is the importance of increasing support for basic research in the processes of aging.

For sound and understandable reasons, much of our gerontological research and policy attention has focused on losses associated with aging. Loss of senses, loss of energy, loss of cognitive powers, et cetera.

But as we have investigated these losses, we have also come to understand that not everyone experiences the losses, and that many conditions once thought to be the normal results of growing older are really the results of diseases or some kind of choices made across the life course of an individual.

At every age within the elderly population, there are a great number of variations in the health status of the individual. These variations suggest an exciting potential and a great challenge, and, that is increasing the number of people who age healthfully. In a sense, extending the health span to match the increase in life expectancy.

The benefits of extending the health span would be significant in terms of improving the quality of lives of individuals and their families, in terms of increasing the capacity of older people to continue to make contributions to our society, and in terms of containing medical expenditures spent on older people.

PREPARED STATEMENT

To increase the health span, we must know more about what is normal aging and what age-related conditions are associated with diseases and other life course choices. Therefore, we recommend that Congress establish a goal of increasing the health span of older people and increase support for basic research in the aging process. Thank you.

Senator WEICKER. Thank you very much, Mr. Cornman.

[The statement follows:]

STATEMENT OF JOHN M. CORNMAN

Chairman Chiles and distinguished members of the Subcommittee, I am John M. Cornman, executive director of The Gerontological Society of America.

My testimony today is directed specifically to the FY 1989 budgets for the National Institute on Aging, the Mental Disorders of the Aging Research Branch at the National Institute of Mental Health, and the Title IV program administered by the Administration on Aging.

Too frequently, growing older is associated with loss--loss of vision, loss of hearing, loss of hair, loss of energy, loss of independence. In fact, people age quite differently. Research supported by the Institute on Aging has found that old age is not a period of uniform or inevitable decline in all physiological and psychological functions. It is rather a period where there is enormous variation among individuals. John W. Rowe, MD, and Robert L. Kahn, PhD, state in a 10 July 1987 SCIENCE journal article, "that attributions of change to age _per se_ may often be exaggerated and that factors of diet, exercise, nutrition, and the like may have been underestimated or ignored as potential moderators of the aging process."

Why such individual variations exist and how the aging process works are only beginning to be understood. Additional research is needed to accurately identify age-related biological, neurological, and physiological changes, such as in brain, renal, and cardiac functioning; changes in vision and hearing; and changes in cognitive functions such as intelligence, learning ability, memory, and decision-making ability. Additional research also is needed on the social and environmental factors which influence and promote healthy aging.

The more we learn about what occurs as part of the aging process and what can be attributed to other factors, the better we understand the potential for improving the health of older people through disease prevention and health promotion. For example, osteoporosis (or the loss of bone density), a crippling disease common among older women, was once considered part of the "normal" aging process. Research has shown that it also is greatly aggrevated by cigarette smoking, heavy alcohol intake, and inadequate calcium. Research findings also are indicating that exercise can possibly increase bone density and thereby help prevent osteoporosis.

For years, older people with any of a broad group of symptoms were diagnosed as "becoming senile, a natural result of growing old." People were told to accept their condition. Today, we know that senility is not a "normal" part of aging.

Research also has shown that much of the cognitive loss in late middle life, previously thought to be intrinsic to aging, can be attributed to other factors and therefore may be preventable. Recent studies further show that such losses of mental function may even be reversible once they occur.

Other discoveries have pointed to the role of proper nutrition in reducing the risk of diabetes, coronary heart disease, and stroke.

What role can research play in the future?

Since the turn of the century, life expectancy has risen dramatically. Due largely to improved sanitation, improved public health, and the control of life-threatening (especially childhood) diseases, life expectancy at birth has increased from about 47 years for men and 49 for women in 1900 to an estimated 71.5 years for men and 78.8 years for women in 1985. Projections suggest that the generation born in the year 2060 can anticipate a life expectancy of 76 years for men and 84.6 for women.

Unfortunately, with the added years has come an increase in diseases more prevalent in later years--dementia, arthritis, deafness, poor vision, cardiovascular disease. As the over 65 age group grows ever larger, the incidence of these diseases, absent discoveries of ways to prevent or cure them, will become ever more prevalent.

We must now shift our attention to extending what Drs. Rowe and Kahn refer to as the "health span," the maintenance of full mental and physical function, as nearly as possible, to the end of life. The challenge will be to develop ways to increase the likelihood that the years being added are satisfying and productive for individuals, their families, and for society as whole.

Research is an essential and basic factor in achieving these goals. Though the outlook for major progress through research is promising; the federal research budget is not. The federal goverment spends more than $100 billion a year for the health care of people over age 65, yet spends less than one percent of that amount on research which could help prevent or cure these tragic illnesses and which could lead to a healthier, more productive older population.

This trend in funding for gerontological research is shortsighted and must be reversed. Discovering what is aging and what is not, dicovering how, why, and under what circumstances apparent age-related declines may be prevented, reversed, or ameliorated could have a significant impact on lowering costs of health care and dependency and on adding to the quality of life of the older person and his or her family. The budget process is our best hope for laying a strong foundation for gerontological research into the next decade and beyond.

Further, even as we strive to understand the aging process in all its complexities, we still must deal responsively to the immediate and pressing problems of older people today and the immediate need to educate and train researchers and providers of service to elderly persons. Demographic trends are clear; the population is growing older. Unfortunately, federal support for applied research and for education of researchers and providers has not kept pace with those trends.

National Institute on Aging. A fiscal year 1989 budget of $260 million for the National Institute on Aging would allow full funding for all 602 of the Institute's grantees. If the Administration's proposed fiscal year 1989 spending level for the Institute is enacted, the NIA will be forced to negotiate across-the-board drastic reductions for all approved research grants for next year.

At present, the National Institute on Aging is able to fund only about 24 percent of the grants recommended in peer review--one of the three lowest funding rates for the National Institutes of Health. Our recommended funding level would allow 37 percent of all applications that are judged meritorious by scientific review panels to be funded. There are a number of areas of research opportunity that are not only of great societal importance, but also offer exciting intellectual challenge: research addressing the fundamental processes of aging; disease and other problems of elderly people; potential for human performance in healthy old age; the societal impact of population aging; and research addressing the lifespan perspective.

National Institute of Mental Health. The National Institute of Mental Health's aging research branch is conducting pioneering research into the causes and effects of Alzheimer's disease. Current funding levels, however, have put 21 highly-rated research projects on hold. We recommend a funding level of $26 million, which would allow the branch to move forward with the projects, including studies of brain imaging in Alzheimer's disease and late onset schizophrenia, depression, and family stress caused by Alzheimer's disease.

Funding in this opportunity budget would allow for expanded studies of treatment for depression in Alzheimer's disease, as well as psychosis, anxiety, and health behavior. The increased funding would provide for the addition of a psychopharmacology research center and would allow additional funds for research training programs.

Administration on Aging--Title IV of the Older Americans Act. By Congressional intent, much of the federal support for applied research on improving the quality and efficiency of programs serving the elderly falls to the Administration on Aging under Title IV of the Older Americans Act. Similarly, much of the federal support for age-related education and training programs for teachers and pracititioners falls under Title IV. Frankly, given the importance of these activities to improving serving delivery, to projecting personnel needs, and to creating the needed pool of education and training. Congress has not paid enough attention to the organization and funding of Title IV programs.

* More efficient service programs save money and improve the quality of services.

* Applied research helps service deliverers solve service delivery problems.

* Well-trained service providers and program administrators are critical to improving program quality and efficiencies.

* Well-trained educators and time-tested educational programs are needed to train service providers and program administrators.

* And, Congress needs on-going personnel-needs projections if it is to have sound information on which to base funding decisions.

Ironically, as budget pressures have increased the need for program efficiencies, as the growth of the elderly population has increased the need for service providers, funding under Title IV has declined in real and actual dollars.

We recognize the pressures on Congress to narrow budget deficits, but even a modest dollar increase in Title IV appropriations, say from $24 million to $34.6 million, would be a cost efficiency of federal dollars.

Health care costs have skyrocketed over the past decade. Investments in research and training hold great potential for reversing this trend, but the investment must be made now if we are to meet the health care challenge of the tomorrow. Thank you Senator Chiles and members of this subcommittee for this opportunity to testify.

BUDGET RECOMMENDATIONS FOR FISCAL YEAR 1989
(dollars in millions)

Agency	FY 88 Allocation	Administration's FY 89 Request'	Opportunity Budget FY 89
National Institute on Aging	$194.7	$204.5	$260.0
National Institute of Mental Health*	$14.6	$15.5	$26.0
Older Americans Act, Title IV	$23.9	$23.9	$34.6

*represents the amount of agency spending on aging related research and training.

STATEMENT OF DANIEL PERRY, EXECUTIVE DIRECTOR, ALLIANCE FOR AGING RESEARCH

Senator WEICKER. And last, for the National Institute of the Aging is Daniel Perry, the executive director of the Alliance for Aging Research. And after that we move to the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

Mr. PERRY. Thank you, Mr. Chairman. My name is Daniel Perry and I am executive director of the Alliance for Aging Research.

I would like to summarize my submitted testimony in a way that responds in part to your excellent remarks to the previous speaker. I ask a rhetorical question. How should our Nation meet the challenge of rising health care costs associated with our rapidly aging population?

Mr. Chairman, I suggest that our options are few. We can continue to pay the bills, presently about $150 billion a year and rising at an alarming rate. We can choose to ration health care and use age as a criteria for denying many forms of life-saving medical treatments.

Shocking as this might seem, it is an option being urged upon us by some medical ethicists and others who believe that age-based rationing is both justifiable and inevitable. We can simply ignore the problem and watch health care expenditures eat up a larger and larger share of America's gross national product. But there is one other choice, and it is one that I believe more closely approximates this subcommittee's aims and purposes.

We can as a nation compute a tiny fraction of the cost of providing health care for the elderly. We can use that fraction as a guide for supporting scientific research into the causes of disease and disabilities that afflict millions of older Americans.

As little as one-half of 1 percent of the $150 billion annual health care bill for the elderly would propel us toward preventions and cures for many conditions of aging which place a crushing cost burden on individuals, families, and taxpayers. That fraction of our costs, if targeted to research opportunities, could produce a bonanza for our society.

On Monday of this week, the Alliance for Aging Research, together with 10 other health care and scientific organizations, released a series of professional judgment budgets, calling for greater investment in aging research.

The members of this newly formed task group for aging research include the American Heart Association, the American Cancer Society, and American Diabetes Association, Paralyzed Veterans of America, and others.

This report represents a consensus, Mr. Chairman, of specific recommendations for fiscal year 1989 for the National Institute on Aging and other Institutes. I would like, for purposes of brevity, to submit this for the record.

Senator WEICKER. It will be included in the record in its entirety.

Mr. PERRY. Thank you. Our alliance also endorses a coordinated national project in human genetic research. We would like to commend Chairman Chiles of this subcommittee and Senator Domenici and others for their strong support and forward leadership toward a national genome initiative.

This molecular roadmap into the causes of human diseases and aging could be the most potent tool for research since the invention of the microscope.

PREPARED STATEMENT

The alliance thanks you for this opportunity to testify, and we look forward to working with your subcommittee in designing a cost effective strategy for aging research, a strategy that will prepare our Nation for the senior boom just ahead.

Senator WEICKER. Mr. Perry, thank you very much for your testimony. We greatly appreciate it.

[The statement follows:]

STATEMENT OF DANIEL PERRY

Chairman Chiles and distinguished members of the subcommittee, my name is Daniel Perry. I am Executive Director of the Alliance for Aging Research, a non-profit, non-partisan, private-sector organization seeking to advance scientific opportunities to help Americans live healthier, more productive lives. The Alliance serves as a network for business executives, leaders of major foundations, and some of the nation's top scientists to broaden the debate of the "Graying of America" to include a science policy which will add life to the years of our older citizens.

I would like to begin by asking a rhetorical question: How should our nation meet the challenge of rising health care costs associated with our rapidly aging population?

Mr. Chairman, I suggest that our options are few. We can continue to pay the bills -- presently about $150 billion dollars a year and rising at an alarming rate.

We can choose to ration health care and use age as a criteria for denying many forms of life-saving medical treatments. This is an option being urged upon us by some medical ethicists and others who believe age-based rationing is both justifiable and inevitable.

We can simply ignore the problem and watch health care expenditure eat up a larger and larger share of America's gross national product.

There is one other choice and it is one I believe more closely approximates this subcommittee's aims and purposes. We can, as a nation, compute a tiny fraction of the cost of providing health care for the elderly and use that fraction as a guide for supporting scientific research into the causes of disease and disabilities that afflict millions of older Americans.

As little as one-half of one percent of the $150 billion annual health care bill for the elderly would propel us toward preventions and cures for many conditions of aging which place a crushing cost burden on individuals, families and taxpayers. That fraction of our costs, if targeted to research opportunities, could produce a bonanza for our society. Increased research likely will lead much sooner to breakthroughs that will cure, prevent or otherwise modify age-related diseases and disabilities associated with the processes of human aging. Are our scientists ready to seize emerging possibilities in aging research. The answer, Mr. Chairman, is yes.

Since this committee last met to consider funding levels for the National Institute on Aging (NIA) and other institutes, a remarkable document was released here on Capitol Hill and sent out to the American public. It is called "Aging Research on the Threshold of Discovery," and it shows what the future might hold for improving the conditions of human aging. In-depth interviews with science leaders representing more than 50 separate disciplines strongly suggest that powerful new tools for combating disease and extending healthy, productive years of life may be here in less than two decades, assuming that support for research is allowed to grow.

On Monday, May 23, the Alliance for Aging Research, together with several other health care and scientific organization including the American Heart Association, the American Cancer Society, the American Geriatrics Society and others, released a series of professional judgement budgets calling for a greater investment in aging research.

It is an overdue and needed investment. In the first few decades of the new century the Baby Boom will become the Senior Boom. If there are no changes in the way people age by the middle of the coming century, we could have more than three times the number of hip fractures, four times the demand for nursing homes, and eight times more dementias than in 1980. Medical costs for the care of a vastly greater number of older persons could overwhelm our entire health care delivery systems.

There are specific steps this subcommittee can take in preparing next year's budget that will help alleviate a health care cost crisis.

We urge this subcommittee to take advantage of opportunities to fund research projects related to a national Genome Initiative to map and eventually sequence human DNA within the next 10 years. This molecular "road map" into the causes of human diseases and aging could be the most potent tool for research since the invention of the microscope. We thank Chairman Chiles and Senator Domenici for their strong support and forward leadership with this important project.

A fiscal year 1989 budget of $260 million for the National

Institute on Aging would allow full funding for all 602 of the institute's grantees. If the President's proposed fiscal year 1989 spending level for the institute is enacted, the NIA will be forced to negotiate drastic across-the-board reductions of up to 16 percent for all approved research grants for next year. Funding the National Institute on Aging at only the level proposed by the Administration for 1989 would have a profound detrimental impact.

Here are a select few examples of the many highly rated research projects which will not be funded as long as only 24 percent of approved NIA projects can be funded:

- research project at the Mayo Clinic to test whether certain back muscle exercises can reduce the risk of osteoporosis of the spine.
- A project from Miami that would carry out work on reducing frailty in some older people by understanding the mechanism of lost strength and coordination, particulary in the arms.
- Research at the State University of New York at Albany to analyze certain proteins produced by aging cells and to compare them to proteins produced in people who suffer from diseases that cause premature aging.

The National Institute of Mental Health is conducting pioneering research into the causes and effects of Alzheimer's Disease. Current funding levels, however, have put 21 highly-rated research projects on hold. An additional $26 million in funding will allow the institute to move forward with the projects, including: brain imaging studies in Alzheimer's Disease and late-onset schizophrenia; studies in depression; and family stress caused by Alzheimer's Disease.

Also of particular note are two important clinical trials scheduled to be conducted by the National Institute of Neurological and Communicative Disorders and Stroke. These clinical trials, involving the testing of important new drugs which could dissolve existing blood clots leading to additional strokes, will have to be postponed unless the center receives a funding increase. One test involves TPA (tissue plasminogen activator), which was approved last year by the Food and Drug Administration for use in the treatment of heart attacks. The clinical trials would examine TPA in dissolving already formed blood clots which can stop blood flow to the brain. The other trail would test the use of heparinoids in preventing the formation of blood clots that can cause additional strokes.

There are many other research opportunities this subcommittee can help advance. Important research into osteoporosis, osteoarthritis, dementia, incontinence and other conditions and diseases afflicting millions of older Americans can bring about a dramatic reduction in frailty, sickness and poor-health. Disease and conditions which inhibit productivity and escalate health care and long term care costs.

Mr. Chairman, for the sake of time I ask that the full report by our task force on aging research funding be included in the record.

Mr. Chairman, we thank you for your support of aging research and look forward to working with your subcommittee in designing a cost-effective strategy for aging research that will move our nation forward.

STATEMENT OF JERAMIE DREYFUSS, LUPUS PATIENT, ON BEHALF OF THE LUPUS FOUNDATION OF AMERICA

ACCOMPANIED BY RICHARD DREYFUSS, ACTOR

Senator WEICKER. We now move to the National Institute of Arthritis and Musculoskeletal and Skin Diseases. And the first witnesses are Jeramie and Richard Dreyfuss, who are here on behalf of the Lupus Foundation of America.

I notice in the prepared statement here it identifies Jeramie as being a Lupus patient, and Richard Dreyfuss as an actor. And I might add, a damned good one. I also notice you are accompanied by my good friend and power broker over here, Jack Valenti.

In any event, it is delightful to have both of you here before the committee, and I look forward to hearing your testimony.

Ms. DREYFUSS. Thank you. My name is Jeramie Dreyfuss. I am a wife, a mother, and I have lupus. I am here today on behalf of the Lupus Foundation of America to impress upon you the urgent need to continue NIH support for biomedical research into the causes of and cure for lupus.

I am pleased and honored by this invitation to speak before this committee, because you have the power to improve the lives of 500,000 Americans who suffer daily with this debilitating disease. You have the power to help us win the fight against lupus, which is claiming the lives of 5,000 each year.

What I am recounting today is not the total of my medical history, but only some of the misunderstood and puzzling episodes that no one could figure out for so long. Over the years I have been hospitalized 28 times and operated on so often for so many different seemingly unrelated reasons that it is hard to keep an accurate count.

Today the reasons do not seem nearly as unrelated as they once did. Through advanced diagnostic and therapeutic methods that have brought about a deeper knowledge of lupus, we can now see a common thread running through each episode that I have experienced. That thread is the immune system and its failure to do its job properly.

At the age of 16 I nearly had my left leg amputated for what appeared to be abnormal growths. I have continued to have major medical problems and surgeries on my leg that have defied explanation.

At the age of 24 I underwent a three vertebrae spinal fusion to alleviate mysterious and excruciating pain. The day following the surgery I suffered an unbearable attack of pain in my abdomen.

After an emergency appendectomy, they informed me that I had indeed had peritinitis, a potentially fatal inflammation of the abdomenal cavity, but my appendix was fine. When I say potentially fatal I mean that the condition has been known to kill its victims within hours of their developing it.

Four years later I suffered five more such attacks. Each time the doctors could not explain it, each time the doctors said it was impossible. Now, what that means is peritinitis is caused by something, but they could never figure out what that something was.

That is not an unusual reaction for a lupus patient to experience because with lupus the damage being done within the body is not always visible to the naked eye. I insisted they take a blood test, and my fears were well founded. My white blood count had soared and peritinitis had reoccurred. Massive antibiotics saved my life.

I was convinced I was going to die in 1978 from some unexplainable illness. I was diagnosed with lupus in 1979. Knowing nothing about the disease, I searched out information at Cedar Sinai Hospital, only to learn that I had life expectancy of 5 years. That is what the medical experts believed about lupus in 1979.

Following the birth of my first child I lost the use of both hands and arms due to a lupus flare that lasted for 2 years. I eventually required surgery on both hands and my right shoulder.

That I am sitting here today is due in large measure to the fact that the American medical and scientific communities are the most advanced in the world. I was treated successfully and I am pulling through so far, but I am one of the lucky ones. I am considered to have a mild case of lupus.

I am here today on behalf of every one of the 500,000 Americans who have lupus, and I am here today for the sake of my son and daughter. My daughter, Emily, who is 4 years old, has already suffered an unexplained high white count called a lupinoid reaction. It terrifies me to think that she might have to suffer the way I have.

PREPARED STATEMENT

For the sake of the next generation, please help us fight diseases like lupus that so threaten the health of the American public. And only research can cure this disease. Only your funding can give us that research. Thank you.

[The statement follows:]

STATEMENT OF JERAMIE DREYFUSS

Introduction

Mr. Chairman and Members of the Committee, my name is Jeramie Dreyfuss. I am a wife, a mother, and a lupus patient. I am here today on behalf of the Lupus Foundation of America, Inc. to talk to you about the desperate need for continued support for biomedical research into a disease that is as idiosyncratic as its name -- Systemic Lupus Erythematosus.

First, however, I want to thank this Committee and the Congress for your support for research in the field of immunology. The support Congress has provided NIH in recent years has helped this country to remain the world leader in medical research and health care. This is something of which all American citizens can be proud.

The Mysterious Disease Called Lupus

I mentioned that lupus is idiosyncratic and it is. It affects over 500,000 Americans and each of us suffers in different ways. No two lupus patients' symptoms are the same. This owes to the fact that lupus, unlike other diseases, can affect virtually any organ or system of the body, either alone or in various combinations. Its symptoms are wide-ranging and often mimic other diseases. In its most severe form, lupus can attack the vital organs including the kidneys, brain, heart, lungs and joints. The disease varies in severity from relatively mild to life-threatening, in part depending on what body systems are involved.

Lupus is a chronic and debilitating inflammatory disease of the connective tissue. It strikes an individual's immune system. Instead of serving its normal protective function, the immune system produces antibodies that attack healthy tissues and organs, in effect, causing the body to become allergic to itself.

I was diagnosed as having lupus in 1979, but the symptoms were apparent well before that. My symptoms have been so wide-ranging and so seemingly unrelated that it took nearly eight years for a proper diagnosis. I've experienced symptoms including severe abdominal tissue inflammation and damage, loss of the use of my hands due to tendon damage, and repeated episodes of dehydration and Sjogren's Syndrome, the so-called "dry eye disease," in which the body simply does not manufacture tears.

Lupus can strike anyone at any age, but it seems to discriminate against women, especially minority women. About one in 700 women between the ages of 15 and 64 is afflicted. Among Hispanic women, one in 410 is afflicted and among Black women, one in 245. All told, the majority of the 500,000 Americans who suffer from lupus are women in their childbearing years. Each year, 16,000 new cases are diagnosed. And, each year, we lose 5,000 people in the U.S. to lupus.

Lupus symptoms include extreme fatigue, unexplained chronic or recurrent low grade fever, diminished appetite and weight loss, nausea, vomiting and abdominal pain, and joint pain or swelling, among others. Not infrequently, women complaining of these symptoms are told that they are suffering from psychosomatic ailments and should consult a psychiatrist. I was told the latter.

Constant fatigue is something that seems to plague most lupus patients. I can't imagine raising two children without the kind of help I have, but I know there are many women with lupus who do not have the same means as I do and are struggling to raise their children. Even more frustrating is the fact that because people with lupus may give the outward appearance of being healthy, the severity of their disease may not be duly recognized by their family and friends.

There are also diagnostic difficulties associated with lupus. The varying symptoms often result initially in misdiagnosis. Far too often people with lupus are told that their symptoms are emotional in nature.

Some victims of lupus have described the disease as a "living hell." Lupus patients have likened their illness to having a severe, chronic case of the flu that does not abate. Everything hurts, and sometimes physical mobility itself can be extremely limited. But unlike those with muscular dystrophy or multiple sclerosis, there may be no outward signs of severe disease.

Perhaps the most discouraging fact about lupus is that, as yet, there is no known cause or cure. The existence of lupus has been known to medical scientists for over a century, and although substantial progress has been made in controlling the disease process, there is no "recovery."

As a lupus patient, I never know when the disease is going to flare. If I go out in the sun, will it flare? And which organ will it strike? Will it be the kidneys this time, threatening life itself? People with lupus live with pain and fear since the disease runs an unknown course.

For me and the thousands of other lupus patients, our only hope lies with the biomedical research currently underway and projected for the future. For us, solving the mysteries of lupus depends on identifying the hard scientific facts of cause, control and cure.

An Agenda for 1989

The critical role of the National Institutes of Health in encouraging and sponsoring scientific study about immune system disorders, including lupus, cannot be understated. With the strong support of Congress, real progress has been made in unearthing the mysteries of the body's immune system, resulting in more advanced procedures for diagnosis, treatment, and, eventually, cure, but continued progress is threatened by: 1) the potential loss of momentum that can result if funds (and thus research support) are cut back or curtailed; and 2) the discovery of new and even more life-threatening immune system disorders, such as AIDS.

In summary, the Lupus Foundation of America, Inc. urges Congress, to:

* Consider FY 1989 allocations in the amount of $224,012,000 for NIAMS to restore parity with other institutes at NIH.

* Consider FY 1989 allocations in the amount of $874,000,000 for the NIAID to expand, initiate and/or support already existing AIDS and non-AIDS related immunology research.

* Increase FY 1989 fiscal allocations for the NIH by at least five percent over FY 1988 levels, to ensure a minimum continued level of support consistent with inflations and other rising cost factors.

* Continue the federal government's support of medical research at levels which, at a minimum, provide for program stability.

* Join with the Lupus Foundation by endorsing the Ad Hoc Group for Medical Research Funding recommendation of $8.2 billion for NIH in FY 1989.

* Fund research project grants at an award rate of 41%,, locking toward a five-year goal of supporting research grants at the 50% level.

* Ensure that the funds allocated for AIDS research must not be "borrowed" or deducted from other biomedical research areas, and reports of publicly funded AIDS research project should be required to show their applicability to other immune system disorders.

* Ensure that the specific allocations for research into the causes of, treatment and cure for lupus, be commensurate with its seriousness and pervasiveness with the United States.

The Lupus Foundation of America pledges to continue its role in encouraging and directly sponsoring lupus research, particularly pilot project which may form the prototype of larger studies eligible for NIH support. We also commit ourselves to a partnership with NIH to promote, disseminate and put to practical and life-saving use the results of these biomedical studies.

Senator **Weicker**. Jeramie, thank you very much. Let me ask you a question from the patient's point of view. Where do we sit on the research? How much further insight do we have in the year 1988 than we had in the year 1978, while you were suffering?

Ms. **Dreyfuss**. Well, I do not think we have come very far in terms of treatment. As far as I know, we are still doing the same things, we are still treating people with the same drugs that they were treating people with then.

Personally, I have had three attacks of bleeding ulcers from the medication, the antimalerial drugs and the cortisone which, though they do not cure anybody, can sometimes alleviate the symptoms. We do not have a cure. We still do not understand what causes it.

Senator **Weicker**. You say there are 500,000 that suffer from this affliction?

Ms. **Dreyfuss**. That is right.

Senator **Weicker**. Well, you better tell the 500,000 that, No. 1, you did your job in testifying. Now they better do their job and get out and vote and elect Congressmen and Senators that are going to go ahead and appropriate the money to do basic biomedical research. It is as simple as that.

Ms. **Dreyfuss**. That is right.

Senator **Weicker**. Have you had heard one candidate, onc Presidential candidate, Democrat or Republican, the whole pile of them, has anybody mentioned anything about basic research or disease or allocating money to health and science? I have not heard it from anybody.

And that is when the agenda has to be set, in election years. So I would suggest that all these groups, not just yours, who plead so eloquently on behalf of life, understand that the agenda, their agenda, can only be set right now. So I hope you do that also.

Richard, good to have you here. Do you have something to further your wife's testimony?

Mr. **Dreyfuss**. The only thing I would like to add is that any money that goes to AIDS, any money that goes to MS, also helps lupus.

But lupus is an unglamorous illness, and needs some strict attention. It is not an illness that grabs a lot of headlines. But it affects so many people in so many ways that it deserves its own disciplined research money.

Senator **Weicker**. Well, I thank you both for being here. Maureen reminds me that Terry Gotthealth in Connecticut has been very active in the lupus movement there.

But I think it is very good of you to take your time, and I have to say to you I am delighted that people that have such outstanding reputations as yourselves would take a few minutes to come here and testify and put the spotlight on an unglamorous disease that nobody knows about. It is very helpful.

After all the doctors get through and the scientists get through, it is good to have persons such as yourselves come here and get the news out there to where the guy in the street understands what we have got confronting us. So thank you so much for coming and taking of your time.

Ms. **Dreyfuss**. We just want people to know that there is hope. Thank you.

Senator **Weicker**. Thank you.

STATEMENT OF BARBARA A. MATIA, PARADISE VALLEY, AZ

Senator **Weicker**. Now, our next witness is Barbara Matia, Paradise Valley, AZ. Barbara, I know that you are a good friend of my sister, Mary Audrey, who has already talked to me about your pending visit.

My sister, incidentally, is a nurse and very much involved herself in health matters, in the hospice that she has been active with, out in Phoenix. So it is good to have you here and we look forward to your testimony.

Ms. **Matia**. Thank you. Your family has done a tremendous amount for health issues.

When the article on Lyme arthritis, or Lyme disease, as it has been more recently called, appeared in Scientific American last July 1987, I immediately saw a correlation between Lyme disease and rheumatoid arthritis.

The part that caught my attention was the fact that the patients with Lyme disease were treated with oral and intravenous antibiotics.

I was fascinated to see that almost all the symptoms that were mentioned in the Lyme disease article were the symptoms I experienced with my battle with severe rheumatoid arthritis, with the exception of joint deformity, which I avoided because I received intravenous tetracycline therapy before the crippling began.

It is also exciting that the National Institute for Arthritis and Musculoskeletal and Skin Disease has identified the infectious theory as a target for its research grant. And I am sure that as a result of that the cause and disease mechanism of rheumatoid arthritis will at some future time be confirmed by irrefutable scientific evidence.

But let us not wait for that to happen before we make available to the general public a treatment program which is based specifically on the infectious theory and which has produced consistent results over a long period of time.

Today I am asking all members of this subcommittee to join together to help arthritis research and its treatment. With all the knowledge that Dr. Brown has provided us from his 50 years of work, with the confirmation of the effectiveness of a similar approach in the case of Lyme disease, and with Dr. Shulman's program announcement to the research community to encourage research on the role of the infectious agents in causing rheumatoid arthritis, this subcommittee has the unique opportunity to change the lives of rheumatoid arthritis sufferers now, rather than 15 years from now.

I urge this subcommittee to mandate a clinical trial of the antibiotic treatment program, which will provide convincing data so that the medical establishment can begin to use this method of treatment.

Most important of all, I am asking that the amount being requested for the fiscal year 1989 budget of the NIAMSD be increased by $15 million, so that research into the infectious theory for rheumatoid arthritis can be conducted without detracting from the other significant work of the NIAMSD. At the present time, the NIAMSD remains the third lowest Institute in funding at the National Institutes of Health.

Eleven years ago I was bedridden with severe rheumatoid arthritis. When you have been as fortunate as I have been to receive the safest and most effective treatment for rheumatoid arthritis, which is the antibiotic, you want to give something back.

PREPARED STATEMENT

I hope my visit here today will encourage you to give all the rheumatoid arthritics in this country the same opportunity that I was given. Thank you very much.

[The statement follows:]

STATEMENT OF BARBARA A. MATIA

I AM BARBARA MATIA OF PARADISE VALLEY, ARIZONA. I APPRECIATE THE OPPORTUNITY TO TESTIFY BEFORE YOU FOR THE FIFTH TIME.

WHEN THE ARTICLE ON LYME ARTHRITIS OR LYME DISEASE, AS IT HAS BEEN MORE RECENTLY CALLED, APPEARED IN SCIENTIFIC AMERICAN LAST JULY, 1987, I IMMEDIATELY SAW A CORRELATION BETWEEN LYME DISEASE AND RHEUMATOID ARTHRITIS. THE PART THAT CAUGHT MY ATTENTION WAS THE FACT THAT LYME DISEASE WAS THE RESULT OF A DEER TICK WHICH CARRIED TO HUMANS AN INFECTIOUS ORGANISM KNOWN AS A SPIROCHETE AND THAT THE PATIENTS WITH LYME DISEASE WERE TREATED WITH ORAL AND INTRAVENOUS ANTIBIOTICS.

IT WAS EXCITING FOR ME TO THINK THAT WITH ALL THE KNOWLEDGE OF LYME DISEASE MAYBE NOW THE INFECTIOUS THEORY FOR RHEUMATOID ARTHRITIS WOULD GET THE ATTENTION IT DESERVED. HOPEFULLY, IT WOULD BRING CREDIBILITY TO ALL THE WORK THAT DR. THOMAS BROWN HAS PURSUED ALONE FOR THE LAST FIFTY YEARS LEADING TO THE CONCLUSION THAT RHEUMATOID ARTHRITIS IS CAUSED BY AN INFECTIOUS ORGANISM CALLED MYCOPLASMA.

I WAS FASCINATED TO SEE THAT ALMOST ALL OF THE SYMPTOMS THAT WERE MENTIONED IN THE LYME DISEASE ARTICLE WERE THE SYMPTOMS I EXPERIENCED WITH MY BATTLE WITH SEVERE RHEUMATOID ARTHRITIS, WITH THE EXCEPTION OF JOINT DEFORMITY, WHICH I AVOIDED BECAUSE I RECEIVED INTRAVENOUS TETRACYCLINE THERAPY BEFORE THE CRIPPLING BEGAN. IN THE FUTURE, RHEUMATOID ARTHRITIS WILL BE UNDERSTOOD TO HAVE SEVERAL STAGES LIKE LYME DISEASE, WITH THE CRIPPLING AND DEFORMITY AS THE FINAL STAGE. UP UNTIL NOW, THE FINAL STAGE WAS THE ONLY STAGE THAT HAS BEEN TRULY UNDERSTOOD AS SERIOUS. WITH THE UNDERSTANDING THAT RHEUMATOID ARTHRITIS IS INFECTIOUS WE CAN HAVE A CLEAR UNDERSTANDING THAT IT CAN AFFECT EVERY TISSUE AND ORGAN IN YOUR BODY. THE DISEASE HAS AFFECTED MY LIVER, SPLEEN, HEART MUSCLE, SKIN, MY EYES (CAUSING BLURRED VISION) AND LUNGS (SHORTNESS OF BREATH). I HAVE SUFFERED EXTREME WEAKNESS AND FATIGUE, INTENSE PAIN AND DEPRESSION WHICH IS TRULY PART OF THE DISEASE. I WOULD DESCRIBE THE DEPRESSION AS HAVING "THE EDGE TAKEN OFF LIFE." IN ADDITION, THE INFECTIOUS THEORY WILL LEAD TO MUCH EARLIER DIAGNOSIS, WITH ANTIBODY BLOOD LEVEL TESTS REPLACING THE LATEX FIXATION TEST WHICH ONLY TURNS UP POSITIVE IN THE LATER STAGES OF THE DISEASE.

IT WAS ALSO EXCITING THAT THE NATIONAL INSTITUTE FOR ARTHRITIS AND

MUSCULOSKELETAL AND SKIN DISEASE HAS AT LAST IDENTIFIED THE INFECTIOUS THEORY AS A TARGET FOR ITS RESEARCH GRANTS. AND I AM SURE THAT AS A RESULT OF THAT THE CAUSE AND DISEASE MECHANISM OF RHEUMATOID ARTHRITIS WILL AT SOME FUTURE TIME BE CONFIRMED BY IRREFUTABLE SCIENTIFIC EVIDENCE. BUT LET'S NOT WAIT FOR THAT TO HAPPEN BEFORE WE MAKE AVAILABLE TO THE GENERAL PUBLIC A TREATMENT PROGRAM WHICH IS BASED SPECIFICALLY ON THE INFECTIOUS THEORY AND WHICH HAS PRODUCED CONSISTENT RESULTS OVER A LONG PERIOD OF TIME. IT MAY BE THAT THE ONLY WAY THIS WILL OCCUR IS AFTER A CLINICAL TRIAL OF THIS PROGRAM IS CONDUCTED.

TODAY, I AM ASKING ALL MEMBERS OF THIS SUBCOMMITTEE TO JOIN TOGETHER TO HELP ADVANCE ARTHRITIS RESEARCH AND ITS TREATMENT. WITH ALL THE KNOWLEDGE THAT DR. BROWN HAS PROVIDED US FROM HIS 50 YEARS OF WORK, WITH THE CONFIRMATION OF THE EFFECTIVENESS OF A SIMILAR APPROACH IN THE CASE OF LYME DISEASE AND WITH DR. SHULMAN'S PROGRAM ANNOUNCEMENT TO THE RESEARCH COMMUNITY TO ENCOURAGE RESEARCH ON THE ROLE OF INFECTIOUS AGENTS IN CAUSING RHEUMATOID ARTHRITIS, THIS SUBCOMMITTEE HAS A UNIQUE OPPORTUNITY TO CHANGE THE LIVES OF RHEUMATOID ARTHRITIS SUFFERERS NOW RATHER THAN 15 YEARS FROM NOW. IN MY FIRST TESTIMONY BEFORE THIS SUBCOMMITTEE IN 1983 I SAID I CONSIDER IT TO BE A NATIONAL TRAGEDY--THAT LITERALLY MILLIONS OF ARTHRITICS MAY HAVE TO WAIT YEARS FOR A TREATMENT PROGRAM THAT IS PRESENTLY AVAILABLE. I URGE THIS SUBCOMMITTEE TO MANDATE A CLINICAL TRIAL OF THE ANTIBIOTIC TREATMENT PROGRAM WHICH WILL PROVIDE CONVINCING DATA FOR THE MEDICAL ESTABLISHMENT TO BEGIN THIS METHOD OF TREATMENT.

MOST IMPORTANT OF ALL, I AM ASKING THAT THE AMOUNT BEING REQUESTED FOR THE FISCAL YEAR 1989 BUDGET OF THE NATIONAL INSTITUTE FOR ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASE BE INCREASED BY $15 MILLION SO THAT RESEARCH INTO THE INFECTIOUS THEORY OF RHEUMATOID ARTHRITIS CAN BE CONDUCTED WITHOUT DETRACTING FROM THE OTHER IMPORTANT WORK OF NIAMSD. AT THE PRESENT TIME NIAMSD REMAINS THE THIRD LOWEST INSTITUTE IN FUNDING AT THE NATIONAL INSTITUTES OF HEALTH. THE RESEARCH WHICH IS CURRENTLY BEING DONE PURSUANT TO GRANTS FROM THE NIAMSD CANNOT JUST BE TERMINATED IN MID-STREAM. AND YET TO WAIT UNTIL THE CURRENT RESEARCH PROJECTS RUN THEIR COURSE BEFORE DIRECTING SUBSTANTIAL FUNDING TOWARD THE INFECTIOUS THEORY IS NOT FAIR TO THE NATION'S RHEUMATOID ARTHRITICS AND IS NOT ECONOMICALLY SOUND. EVERY DAY LOST COSTS AMERICAN BUSINESS SUBSTANTIAL SUMS IN LOST PRODUCTIVITY.

WHEN YOU HAVE BEEN AS FORTUNATE AS I HAVE BEEN TO HAVE RECEIVED THE SAFEST AND MOST EFFECTIVE TREATMENT FOR RHEUMATOID ARTHRITIS WHICH IS ANTIBIOTICS, YOU WANT TO GIVE SOMETHING BACK. I HOPE MY VISIT HERE TODAY WILL ENCOURAGE YOU TO GIVE ALL THE RHEUMATOID ARTHRITICS IN THE COUNTRY THE SAME OPPORTUNITY THAT I WAS GIVEN. THE DECISION IS YOURS!

Senator WEICKER. Barbara, thank you very much. I want to say something. I will be glad to talk to personnel of the National Institutes of Health about your request.

But, I have to say to you, and I think Senator Chiles feels the same way I do, that we have never intruded politics into science. We have not mandated clinical trials. I believe that is the policy of Chairman Chiles also. It is my policy.

I just feel that the very thing that I got through talking about a few minutes ago, about politics overwhelming science, would come to pass if we used the power of the Chair for that purpose. That does not mean to say that we will not be glad to go ahead and talk to the individuals at NIH.

But I have got to say to you that I would not be part of a mandate from the committee vis-a-vis a clinical trial. My job is to make sure there is enough money in the pot, to make sure that many more clinical trials can take place, one of which very well might be yours that you are seeking here. And I have no hesitation in talking with the Institutes.

But I just wanted to make that point because I am sure you would love me to go ahead and do what you asked me to do, but I really cannot do it.

Ms. MATIA. I think the most important thing is to increase the funding at NIAMSD, and that their first priority is research. It is so difficult to let the arthritics wait for the program because they are the ones suffering.

I think the reason we have trouble getting clinical trials funded is because of low funding priorities. So if you can work on increasing the funding that would be appreciated. Thank you.

Senator WEICKER. Thank you very much, Barbara.

STATEMENT OF BARBARA BUTLER, COALITION OF PATIENT ADVOCATES FOR SKIN DISEASE RESEARCH

ACCOMPANIED BY:

KAREN EISENBERG, NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

WILL WACHTEL, NATIONAL PSORIASIS FOUNDATION

DIANE WILLIAMS, UNITED SCLERODERMA FOUNDATION, INC.

MARTHA WOODHOUSE, EXECUTIVE DIRECTOR, NATIONAL CONGENITAL PORT-WINE STAIN FOUNDATION

ALLEN C. LOCKLIN, THE NATIONAL VITILIGO FOUNDATION, INC.

RICHARD LONG, NATIONAL ELOPECIA AREATA FOUNDATION

Senator WEICKER. I notice, incidentally, that we have some young people that I imagine are here to testify.

If they are, I know how hard it is to sit through anything of length, especially how hard it is to sit through anything that goes on in the Senate of the United States. So, if they are here, I would like to give them an opportunity to present their testimony.

Are any of those young persons that I see out there scheduled to testify? No? OK, well, I just wanted to make sure that—you are scheduled to testify? Well, why do you not go ahead and do your testifying? You are part of a group? Get the group up here.

Now, here we have a group. This is a group, a large group. Now, we have seats for everybody. We will get a seat for you, no question about that. Can you tell me who this group is here?

Ms. **Butler**. Yes; Mr. Chairman, good morning. My name is Barbara Butler, and my affiliation is with the Lupus Foundation of America.

Today, however, I speak to you as a representative of the Coalition of Patient Advocates for Skin Disease Research, a group of national lay skin disease organizations which are principally directed and supported by patients and their family members. We represent diseases that are potentially disfiguring, disabling, and often fatal.

Our interest as a coalition is seeing that basic skin research is encouraged and supported so that new treatment and eventual cures can be found for those skin diseases which now afflict an estimated 60 million Americans.

We are most grateful to the Senate for its support of the creation of the National Institutes of Arthritis and Musculoskeletal and Skin Disease, and certainly for adding skin disease in the title of the Institute.

Also to Dr. Lawrence Shulman, the Institute's Director, for his support of skin disease research in his recent decision to fund two dermatology core centers. This new Institute has offered tremendous hope for the patients and families represented here today.

It is, however, important that the Institute be sufficiently funded. Currently, the new Institute has a lower award rate than others. We ask that this discrepancy be rectified so that this important new Institute, which you helped to create, is able to have an award rate equal to the NIH average.

PREPARED STATEMENT

Today, several members of the coalition have come with me to speak to you about their concerns and interests. On behalf of those here today, as well as those who are unable to attend, we wish to thank you for your support of skin disease research, and how very much it means to so very many to know that you have cared enough to help. Thank you very much.

[The statement follows:]

STATEMENT OF BARBARA BUTLER

My name is Barbara Butler. I am a representative of the Coalition of Patient Advocates for Skin Disease Research (CPA/SDR), which is a coalition of national lay skin disease organizations which are principally directed and supported by patients and their families whose lives are directly affected by skin disease. For most of these patients, there are either no, or few treatments. Yet, these diseases are frequently fatal and commonly severely disabling and disfiguring.

Our interest as a Coalition is seeing that basic skin research is encouraged and supported so that new treatments and eventual cures will be found for all those skin diseases which now afflict an estimated 60 million people in the United States. We are appreciative of the extreme interest the Senate has shown in the needs of the various skin disease organizations represented here today, and appreciate its support. We are most grateful to the Senate for its support of the creation of the NIAMS and for adding "Skin Disease" in the title of the Institute, and to the Institute Director for his support of skin disease research and his recent decision to fund two dermatology core centers. These centers will provide a technology and capital base through which broad-based skin disease research can be conducted and which will serve to attract scientists from the newest scientific disciplines and the newest technology to the problem of skin disease.

The new Institute offers the best hope for the patients and families represented here today by members of the Coalition. That is because it offers funds to attract new and young investigators to the study of these diseases.

In order for our organizations to be effective in generating interest among young and new scientists in skin research, we need to assure them that there is funding available to them that can support their kind of work. For example, currently most of the organizations represented here offer small seed money grants and fellowships to attract new people, new scientists, and to support new projects. We need the funds that NIH can provide offer the possibility of support to these young scientists for add-on work that might grow out of the seed money projects. But it is important that the Institute be funded sufficiently. Currently, the new Institute has a lower award rate than any other Institute and also one of the lowest pay lines. For it to be equivalent to the other Institutes, it needs additional funds. We ask that the Senate increase the funding of NIAMS to the level of $224,000,000. We feel this funding level is vital to maintaining a momentum of growth in the ability in dermatology research.

Today, several members of the Coalition have come with me to speak to you. They would like to present to you background on their concerns and their interest in NIAMS.

On behalf of all of the organizations represented by the Coalition, I want to thank you for your support of skin disease research and urgently request you to fund the new Institute at a level that makes it equivalent to the other Institutes.

STATEMENT OF LINDA MORGAN

Ms. MORGAN. Honorable members of the committee, my name is Linda Morgan. I am a volunteer member of FIRST, which is the Ictheosis Foundation, speaking for myself and thousands of fellow members.

Ictheosis is the name for a group of almost 40 related skin diseases in which severe scaling of the skin is the primary symptom. It is a genetic disease.

Every year almost 17,000 more people are born in the United States with one of these diseases, facing lives of limited productivity and social interaction because of their disability and disfigurement.

There is very little research and certainly no cure for any of these diseases. In the most severe forms of the disease, babies die shortly after birth from dehydration and infection.

Some forms of ictheosis cause mental retardation, immune deficiencies, deafness, lack of body temperature control, raw blisters, and bone deformities, as well as psychological devastation that can accompany bodily disfigurement.

This picture is Dennis from San Francisco, CA. His life and Ryan's life matter. You can help Dennis and Ryan and thousands of children and adults all over America by insisting on a funding level of $224 million for NIAMS, and just as important, by funding an additional $17 million to correct the current disparity NIAMS' projects face.

Only one in four of our research projects are funded, even though these projects are rated higher than other NIH projects. And the other projects do get funded, even though ours are rated higher.

Please create parity for NIAMS' projects within NIH for research and for progress, and help us by using the power you have to save lives like Dennis' and Ryan's by making the medical research establishment focus on ictheosis. Thank you.

Senator WEICKER. Linda, thank you. What is the young man's name?

Ms. MORGAN. Ryan.

Senator WEICKER. Nice to have you here, Ryan.

Ms. MORGAN. He is pleased to be here. He usually speaks very well.

Senator WEICKER. Please, just proceed however you want to do this.

STATEMENT OF WILL WACHTEL

Mr. WACHTEL. My name is Will Wachtel, and I am with the National Psoriasis Foundation. I am 35, and I have had psoriasis since I was 17, and so I know very well the emotional impact of this disease.

It also has a physical impact, but for most people the emotional impact is much greater. To the point where some people either follow through with suicide or very seriously contemplate it.

Without taking a lot of time, I do have my written testimony which goes into detail, what we originally were asking for was $224 million for the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

We realize in this year that that might not be possible, probably is not possible. We would like to achieve parity with the other Institutes, as was mentioned in the previous testimony. Our pay lines and our award rates have been lower, and we would like to get them up.

That, of course, would require an increase over the President's budget. We feel that this is needed because we need to send the message to our young people that biomedical research is a field that they can go into that has promise. I think that is probably the most important thing.

Second, we need to maintain, it has been mentioned here several times that the United States is the world leader in science and technology, and I think we need to maintain that, and that does require expenditure of money.

PREPARED STATEMENT

And most importantly, too, is that we need to get many patients off dependency on the health care system. Because many patients are partially or totally disabled, they cannot contribute to our tax base. If we can get them off the dependency of the health care system, that can help pay for the research in the long run.

I would like to thank you, Senator Weicker, and this committee, for the past support. And I do appreciate it. Thank you very much.

[The statement follows:]

STATEMENT OF WILL WACHTEL

My name is Will Wachtel. I am 35 years old and I have had psoriasis since I was 17. I am here today as both a patient and a member of the Board of Trustees of the National Psoriasis Foundation (NPF) to request funding for the National Institute of Arthritis, Musculoskeletal and Skin Diseases at a level of $224 million. We believe that this amount is essential to maintain the viability of this institute which has had the lowest paylines and award rates of any of the National Institutes of Health. While this amount is considerably higher than the proposed funding level, it is estimated that it will require $224 million to bring NIAMS up to the overall NIH paylines and award rates. We cannot allow this institute to fall further behind if we expect it to produce significant scientific discoveries.

Expressing it in simple terms, psoriasis is a disease where the skin cells overproduce. The skin cells multiply so fast that they cannot be shed at the same pace, resulting in elevated lesions which appear reddish and are often covered with scales.

It is estimated that 3 to 8 million Americans are afflicted with psoriasis, meaning that 1 person in every 30 to 80 suffers from the consequences of this disorder. The extent of psoriasis in individuals can range from being minimal to so severe as to be functionally disabling and even life-threatening. And since both the severity and duration of bodily coverage can vary widely, it is safe to say that the only thing predictable about psoriasis is that it is unpredictable.

One thing that I can tell you is that psoriasis causes devastating psychological effects. In fact, in the majority of cases, the emotional impact is more of an impediment than the physical impact. Because psoriasis is visible and our skin is the means by which we initially define ourselves to others, people with this affliction feel anxious about being accepted in a society that places a high value on unflawed physical appearance. This further hinders one's self-acceptance and makes coping with this disease more difficult.

For myself, it is only in the last several years that I have learned to overlook people's stares and to focus on a positive self-image and to overcome self-imposed limitations. Yet it still bothers me when I overhear a curious child ask a parent "What are those spots on that man?" And as a single person, it is a challenge to meet single women, especially in light of the fears about AIDS present today.

These concerns and feelings are compounded by the fact that the public doesn't know that psoriasis is neither contagious nor curable; this leads some psoriatics to isolate themselves and to even contemplate suicide. For example, I would like to quote excerpts from a letter the NPF recently received from a 21 year old man; we could not respond directly to him as he signed it only as "Confused of Brooklyn". He states "I have hidden this disease from most of the people I know except my immediate family . . . My father has spent thousands of dollars on me between hospitals, medicines, doctors, & UVB treatment but nothing worked. I get better two months a year but it all comes back . . . I haven't gone swimming or to the beach in 8 years . . . My friends know I have some kind of problem but are not sure what it is. I try to keep it a secret because of all the AIDS & Herpes going around."

He continues, " I had and still have trouble finding girls in my life. I keep to myself & try to figure out problems on my own. I know I have a disease but do not know why. I'm giving up on myself slowly. I am at the point in my life where I can't stand it any more. I thought of suicide but can't bring myself to it. My psoriasis holds me back from doing a lot that I would like to do. I think I'm going nuts. I don't do drugs or smoke or drink and am a pretty good person . . . My folks give me everything I need & I am not deprived of anything except one thing - my health. I pray to God every day for it to return before I totally flip out or do something stupid. I am confused & do not know what to do."

Unfortunately, the NPF receives quite a few letters from people feeling desperate. The tragic thing about this one is that this man is in the prime of his life and he has thought about ending it. We have to be able to give hope to this man and others like him if we expect them to become productive members of society.

In terms of hope and progress, scientists have recently been looking for genetic factors in psoriasis and ultimately hope to find the specific genes involved with psoriasis. Furthermore, there have been clues that psoriasis is related to immune system function and scientists are now realizing that the skin is an active organ and not just a covering. Research into these areas could lead to vital information in dealing with AIDS and other diseases of the immune system.

Therefore, it is crucial that the paylines and award rates of NIAMS be raised to be on a par with the overall NIH levels. In 1987, NIAMS had a payline of 147 while NIH was 174; for that same year, award rates were 30.8% for NIAMS versus 38.3% for NIH. The estimates for 1988 are a NIAMS payline of 140 and an award rate of 25.2% while NIH would have a payline of 160 and a 33.8% award rate. I strongly urge you to break this pattern of NIAMS having consistently lower paylines and award rates than the rest of the institutes encompassed in NIH. As I stated earlier, it is felt that 224 million dollars is needed to establish parity with the other institutes.

I know that it is easy for me to request this level of funding and that you have the tough job of finding those funds. However, I believe that we must view increased funding as an investment in the future in several ways. One, so that we can send the message to our young people that a career in science and biomedical research is both possible and important. Also, if we want the United States to continue to be the world leader in science and technology, we must be willing to spend the money required to maintain our edge. Most importantly, we want to find a cure or at least the most widely effective treatment for people with psoriasis so that we can make them less dependent on our health care system. The economic payback will be realized by the increased number of people who are able to contribute to society.

In conclusion, please consider the paylines and award rate disparity of NIAMS in appropriating the funds so that the goal of $224 million for this institute is reached.

I thank you for the time and consideration you have given me today and especially for your past support of NIAMS and NIH, which has produced results that have improved the quality of life for people with psoriasis. The form of treatment known as PUVA (the drug Psoralen and Ultra Violet type A light) is just one example of those results. I speak for the members of the National Psoriasis Foundation in extending my gratitude for the compassion you have shown today and in the past.

STATEMENT OF KAREN EISENBERG

Ms. Eisenberg. Hello, my name is Karen Eisenberg, and I am here today representing the National Foundation for Ectodermal Dysplasias.

As a parent of a child with ectodermal dysplasias, I have firsthand knowledge of the trials and tribulations which confront these patients on a daily basis. The ectodermal dysplasias are characterized by abnormalities at at least two derivatives of the skin.

They may include sparse hair, eyelashes, and eyebrows, malformed fingernails, missing teeth, an absence of sweat glands, deficient tears and saliva, poorly functioning mucous membranes, hearing and sight deficits, missing fingers and toes, clefting of the lip and palate, eczema, and dry cracking skin.

Thirty percent of those affected with the most common form of ED do not survive their infancy. Those affected by ED must live in an air-conditioned environment. Precautions must be taken to prevent major medical catastrophes related to high fevers and infection.

Skin care and dental treatments are continuous and lifelong. My little boy received his first set of dentures at 18 months.

At present, no specific research is being done on ED. No tests are available which will identify those individuals who carry the genes for ED, with the potential of passing them on to their offspring.

Procedures such as dental implants are being done on children as young as 5 years of age, even though no data has been collected supporting successful treatment in the long term. In reality, these children are serving as human models.

PREPARED STATEMENT

I really appreciate this opportunity to be here and to speak with you. I feel it is really necessary to add $17 million above the President's proposed budget to assume the level of grants funded is brought to parity with other Institutes at NIH. Thank you.

Senator WEICKER. Thank you very much.

[The statement follows:]

STATEMENT OF KAREN EISENBERG

Good morning! My name is Karen Eisenberg. It is my pleasure to serve as a volunteer representing the National Foundation for Ectodermal Dysplasias. My purpose in providing testimony to this committee is to briefly share a bit of information about the ectodermal dysplasias and the problems experienced by those who are affected. As the parent of a child with hypohidrotic ectodermal dysplasia I have first hand knowledge of the trials and tribulations which confront these patients on a daily basis.

The ectodermal dysplasias are characterized by abnormalities in at least two derivatives of the ectoderm. These may include; sparse hair, eyelashes and brows; malformed fingernails; multiply missing teeth; an absence of sweat pores; deficient tears and saliva; poorly functioning mucous membranes; hearing or sight deficits; missing fingers or toes; clefting of the lip or palate; eczema and dry cracking skin. Additional problems such as frequent upper respiratory infections and immune system deficiencies are related to ED. 30% of those affected by hypohidrotic ectodermal dysplasia, the most common form of ED, will not survive their infancy.

Those affected by ED must live in an air conditioned environment at home, at school and at work. Precautions must be taken to prevent major medical catastrophes related to high fevers and infection. Skin care and dental treatments are continuous and life long. A child with few teeth may be fitted with dentures as early as age two with frequent denture changes expected until the child reaches adulthood. Learning difficulties associated with ED are most probably related to the patient's inability to perspire.

At present no disease specific research is being done on ED. No basic science has been initiated which would help us understand the ectodermal defect responsible for the affects of ED. No tests are available which will identify those individuals who carry the genes for ED with the potential for passing them on to offspring. Procedures such as osseointegrated implants are being done on children as young as five years of age even though no data has been collected supporting success for such treatment in the long term. In reality these children are serving as human research models.

I mention all of this to underscore our support for the National Institute of Arthristis, Musculoskeletal, and Skin Diseases and the National Institute for Dental Research. I respectfully request your consideration of an amount of $224,012,000 for NIAMS funding for the year 1989 and an amount of $135 million dollars. Funding at such levels may one day allow research into life threatening disease such as ectodermal dysplasia which currently go unnoticed. Our National Insitutes of Health are vital to the health and welfare of all of this nation's citizens. Dollars spent at NIH are invariably saved from dollars that are otherwise lost in wages and escalating health care costs.

I appreciate having this opportunity to talk with you and thank you for your past support of the National Institutes of Health.

STATEMENT OF MARTHA WOODHOUSE

Ms. WOODHOUSE. Good morning. Before I start, I would just like to say how moved I am by so many of the comments here today.

Senator Weicker and members of the subcommittee, I am Martha Woodhouse, executive director of the National Congenital Port-Wine Stain Foundation.

I am here today to represent my daughter, Sarah, who was diagnosed at birth as having two rare disorders associated with the port-wine stain birthmark. One being the Sturge-Weber syndrome, the other being the Klippel-Trenaunay Weber syndrome.

Last year I had the honor of speaking before you and sharing my experience. I explained how the birthmark could be much more than a cosmetic problem. It is a very serious vascular malformation.

In my case, an early prenatal diagnostic test was done called the chorionic villus biopsy sampling. I witnessed an early intrauterine environmental accident as my daughter was hit during the testing procedure.

Sarah was born with a development arrest of an otherwise healthy umbilical cord, and a severe retention of her primitive capillaries which manifested themselves as a port-wine stain covering 40 percent of her body.

The complete case study and supporting of my research can be found in the February 14 issue of the CVS Newsletter, published by

Laird Jackson, M.D., at the Jefferson Medical College of Thomas Jefferson University.

Treatment of the Sturge-Weber syndrome, the Klippel-Trenaunay Weber syndrome, and the port-wine stain is currently symptomatic and supportive. Education is critical for the benefit of these children. Many cases go undiagnosed, and the damage, once it occurs, is irreversible.

Laser technology has developed many promising therapies for lightening or removing the port-wine stain with minimal discomfort and scarring. Laser treatments are usually recommended before the onset of puberty, because with puberty comes hormonal changes that cause a deepening of the color of the port-wine stain and an actual thickening of the skin.

I want to thank you for supporting skin disease research, and the creation last year of the dermatology core centers. I urge you to increase funding to NIAMS at the level of $171 million, which includes an additional $17 million over the proposed budget for this year.

The additional funding is essential to ensure that the level of grants funded is brought to parity with the other Institutes at the NIH.

Biomedical research is greatly needed to study the etiology of the port-wine stain, including Sturge-Weber and the Klippel-Trenaunay Weber syndromes.

Biomedical research is needed to study the long-term effects of the new tunable-dye laser treatments on the genetic material in the skin cells themselves, to ensure the future health of those treated presently.

A study is also needed to compare the various types of lasers with the best age for treatment and taking into consideration the various skin properties.

PREPARED STATEMENT

Anyone who thinks that this and other skin diseases are not serious disorders has not taken the time to consider the psychological, interpersonal, and vocational consequences of these different afflictions. And nobody should underestimate the impact of the various skin diseases on us as a nation. Thank you.

Senator **Weicker**. Thank you very much for your testimony.

[The statement follows:]

STATEMENT OF MARTHA WOODHOUSE

I am Martha Woodhouse, Executive Director of the National Congenital Port-Wine Stain Foundation. I have worked in the field of human services as an educator since 1969. I graduated from Columbia University in 1985, with a Master's in Educational Administration.

Last year I had the honor of speaking before you and sharing my experience in learning the meaning of the "Birth-Mark", called a Port-Wine Stain. I explained how this birthmark was not merely a cosmetic problem, but a serious vascular malformation.

A Port- Wine Stain is caused by an abnormal network of blood vessels which are retained in a primitive state due to an interruption of the normal developmental pattern. This vascular malformation, as seen on the surface of the skin as a Port-Wine Stain, may be caused by an early intra-uterine environmental accident.

In my case, an early pre-natal diagnostic test was done called the Chorionic Villus Biopsy Sampling (CVS). The procedure itself, which aspirates tissue at the site of the developing umbilical cord, was not performed carefully. I witnessed an early intrauterine environmental accident as my daughter was thrust upward during the procedure.

Sarah was born with a developmental arrest of an otherwise healthy umbilical cord, and a severe retention of primitive capillaries which manifested themselves as a Port-Wine Stain that covered 40% of her body.

The complete case-study and supporting research can be found in the February 14, 1988 issue of the CVS Newsletter, published by Laird Jackson, M.D.; Jefferson Medical College of Thomas Jefferson University.

Sarah was diagnosed at birth as having two rare disorders associated with the Port-Wine Stain. This diagnosis was made based on the pattern and distribution of her birthmark. The Sturge-Weber and the Klippel-Trenaunay Weber Syndromes are rare and usually occur separately.

The Sturge-Weber Syndrome is usually diagnosed when the Port-Wine Stain is located around the eyes and/or on the forehead, in the area known as (V1). When the underlying vascular defect involves the organs of the eyes, it often manifests in the form of glaucoma.

If the brain is involved, seizures are often severe and difficult to control with anti-convulsants. The seizures may cause brain damage, retardation and hemiparesis so severe that a surgical procedure called a hemispherectomy is considered the best option.

Klippel-Trenaunay Weber is diagnosed when the Port-Wine Stain covers a large portion of one or two limbs, usually on the same side of the body, involving the deeper, underlying blood vessels. This can cause excessive growth or atrophy of the soft muscle tissues and bones. A variety of complications can include: varicose veins, curvature of the spine, thrombophlebitis, abnormal bleeding or paralysis.

Treatment is currently symptomatic and supportive. Education is critical for the benefit of these children. Many cases go undiagnosed and the damage is irreversible. Children with Sturge-Weber/Klippel-Treanaunay Weber must be monitored by pediatric dermatologists, opthamologists, neurologists, and orthopedic surgeons, and may require special education.

Laser technology has developed promising therapies for lightening and/or removing the Port-Wine Stain with minimal discomfort and scarring. Laser treatments are recommended before the onset of puberty because, with hormonal changes, comes a deepening of the Port-Wine Stain color and a thickening of the skin. As a result, treatment becomes more difficult and often less effective.

I am here today on behalf of my daughter, Sarah, and The National Congenital Port-Wine Stain Foundation, to thank you for supporting Skin Disease Research and the creation of (2/3) Dermatology Core Centers.

I urge you to consider increased funding for the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). We are asking for your support at the level of $224,012,000 for Fiscal Year 1989.

The two dermatology core centers funded are greatly needed to establish a baseline for biomedical research. Major strides can be made in understanding the causes of these skin diseases and can help develop safer and more successful laser treatments.

Biomedical research is greatly needed to study the etiology of the Port-Wine Stain, Sturge-Weber and Klippel-Trenaunay Weber Syndromes.

Biomedical research is needed to study the long-term effects of the newer tunable-dye laser treatments on the genetic material in the skin cells, for future health.

And a study is needed to compare the various types of lasers with the best age for treatment and taking into account the various skin properties.

Anyone who thinks that this and other skin diseases are not serious disorders, has not taken the time to consider the psychological, inter-personal and vocational consequences of this type of affliction and should not underestimate its impact on us as a nation.

The information I have presented today is based on the research currently available. Unfortunately, much more remains unkown than is known at the present time. And, most importantly, what is the prognosis for our daughter and the other children born with Port-Wine Stain, Sturge-Weber Syndrome, and Klippel-Trenaunay Weber Syndrome?

Only continued and increased medical and scientific research can shed light on these and other crucial questions. We must do all we can to insure that research continues to protect our nation's children from future mistakes.

Your support for this valuable research may bring us closer to the day when children and their families will not suffer unnecessarily as we have. Each year 0.3% of our nation's newborn children have a Port-Wine Stain (nevus flammeus). This translates to about 7 million afflicted Americans.

Thank you for your continued support and consideration of our request.

STATEMENT OF RICHARD LONG

Mr. LONG. Mr. Chairman, my name is Richard Long. I am Washington representative from the National Alopecia Areata Foundation.

There are over 2 million people estimated to have alopecia areata, and one of them is a member of my family. For most people it is the body attacks hair follicles and it causes the hair not to grow.

It is not male pattern baldness or anything associated with that. It is quite simply that the body attacks part of itself, and the body then loses the advantages of having that. And the pain that is accompanied by it.

We are here today with our skin-related disease coalition partners to ask you to put money into the National Institutes of Health's program so that there can be a synergistic effect between and among all the studies that are being done in skin and its related disorders, so that people who suffer from the diseases that we are representing here today can benefit from that synergistic effect.

PREPARED STATEMENTS

Parity has been talked about. We would actually like to see more in the long-term, because through that effect more can be learned and understood. Thank you.

[The statements follow:]

STATEMENT OF RICHARD LONG

Mr. Chairman and members of the Senate Subcommittee on Appropriations for the Departments of Labor, Health and Human Services and Education, I am Richard Long, Washington Representative for the National Alopecia Areata Foundation. I am here today with representatives of the Coalition of Patient Advocates for Skin Disease Research to discuss with you the need for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to fully fund the dermatological centers that were begun last year.

Alopecia Areata and other forms of alopecia are diseases that affect the development of hair on the human body. The National Alopecia Areata Foundation is a non-profit organization dedicated to finding a cure for this disease.

It is estimated that over two million people, children and adults of all racial and ethnic backgrounds, suffer from alopecia. Some lose only a small patch of hair on a part of their body, while others lose their entire head of hair. Other people lose all of their body hair. Why does this happen? What effect does this have on the individual and what can be done about it? In my testimony today I hope to put these questions into perspective.

First, what effect does hair loss have on the individual?

Alopecia Areata is the name used to describe a condition in which the hair follicles of the human body do not grow. For some the condition is only the size of a quarter, and temporary. For others it is much worse. Hair provides the body with insulation and protection. Part of this protection is psychological. For those people with Alopecia, the loss of all of their hair causes psychological pain and suffering.

For children the psychological pain can be especially acute, and can influence the development of their self-image and self-worth. School children with the condition have been suspended from school or placed in classes for handicapped children, solely on the basis of having Alopecia Areata.

When an adult first discovers that he/she is losing his/her hair a trip to the physician is the first action. Many doctors identify this condition as being stress-related, or being triggered by a stressful event, and prescribe drugs to reduce stress. Some physicians prescribe cortisone injections to replace each lost hair follicle -- a treatment that is painful, temporary, and with many unknown side effects. A few doctors have even prescribed the use of mayonnaise, which unlike the other treatments has few side effects, but is also ineffective. My point is our understanding of this disease is rudimentary at best.

Once an individual has come to terms with the fact that he/she has lost his/her hair, he usually seeks some type of cosmetic help. Many need wigs to protect their scalp from the elements or to ease the social effects of hair loss. Unfortunately, while it is possible to prescribe wigs for other types of hair loss diseases, insurance companies do not view Alopecia Areata as sufficient cause for reimbursement. In the case of Alopecia Areata wigs should be considered prostheses just as artificial limbs are considered prostheses.

For a child and its parents, Alopecia Areata causes pain. Other children tease, and parents feel guilty and frustrated at their lack of information and effective treatment. As noted earlier some schools even subject the child with Alopecia to the special education program because they are seen as handicapped, thus further damaging the fragile world of the child with a disease of unknown origin. The pain that a child can suffer is real. The pain that their parents feel is real.

How does this happen?

Alopecia Areata has been identified as a disease since the last century. Louis the XIV may have suffered from the condition. It is not caused by stress. It has not been found to run in families in any predictable pattern, nor does it seem related to any factor in the environment. Simply put, the hair is identified by the body as a foreign matter and the immune system attacks it; in a sense the body attacks itself. Effective treatments can not simply treat the hair, skin, or the follicle. Treatment needs to focus on the complex interactions within the immune system. Successful treatment(s) have yet to be discovered, but the answers will most likely be the result of multidisciplinary research.

Future courses of action

The need for multidisciplinary research and model building is why we are here today. The support of the Congress in funding two centers for dermatological research is a critical step in finding a cure for Alopecia Areata. Centers can bring together researchers from many differing fields of study in a synergetic effort that results in the development of researchable models on skin, hair, and the immune system. Only by supporting the two current research centers and expanding the number of centers can the work be brought together and effectively studied.

The Foundation has already funded many small research grants to develop the interest of professionals for Alopecia Areata as a field of research. They have been conducting small studies to pave the way for theoreticians to integrate this new data into models for future research.

From previous research we have learned that the hair follicle is not dead. We have learned that the immune system is a key factor in the complex disease known as Alopecia Areata. However, much more needs to be done.

At a minimum level, the federal government needs to sustain the two centers it funded last year for dermatological research by NIAMS. Research out of these centers can provide the basis for future study on how the skin and its allied systems work. Then, a model can be developed on Alopecia Areata and possible solutions to the problem of this disease can be researched.

The support of Congress is critical. With continued support more interest in the disease will be generated among professionals who, in turn, will dedicate more time and attention to a problem that affects many Americans.

Thank you for your time and interest in finding a cure for Alopecia Areata and the other skin-related diseases represented by the Coalition of Patient Advocates for Skin Disease Research. Your support of NIAMS and its dermatological research centers has been and continues to be critical.

I look forward to answering any of your questions.

STATEMENT OF DIANE WILLIAMS

Mr. Chairman, I am Diane Williams, a scleroderma patient and founder of the United Scleroderma Foundation, Inc. I appreciate the opportunity to present this testimony of behalf of all scleroderma patients.

At the time of my diagnosis in 1969 knowledge of scleroderma, even in the medical community, seemed very lacking. I had suffered for two years before being properly diagnosed and then found there was no scleroderma literature written for lay people. I knew of no other persons with this disease, and felt thoroughly alone even though there are hundreds of thousands of cases in the United States.

With this lack of knowledge in mind, The United Scleroderma Foundation set out to change the situation by publishing scleroderma literature, presenting educational workshops, and instituting public awareness programs. Our goals, then as now are: patient contact, public awareness, and funding scleroderma research. Your continued funding of research centers gives us all reason to hope that the elusive clue to solving the mystery of scleroderma will be found!

Scleroderma literally means "hard skin", but in its progressive form can involve the entire body. It is a disease of the connective tissue and thought to result from narrowing of blood vessels, leading to fibrosis of skin and multiple organs. The skin becomes tight and causes problems ranging from difficulty opening and closing the mouth, to wide-spread crippling. The hands and other extremities are subject to ulcerations which, because of impaired circulation, are difficult to heal. Scleroderma patients are prone to infections because of calcium which builds up and protrudes through the skin. Gangrene and amputations are a continual worry.

Scleroderma is a devastating disease with many symptoms which can vary in intensity in a short time. Severe internal problems involving lungs, gastrointestinal tract or kidneys will require the use of oxygen, tube feeding, or dialysis. Because prognosis is difficult in most cases, the patient is confronted with the added problem of fear of the unknown; therefore, emotional support is also a major factor in the treatment of scleroderma.

In the twelve years since our inception the United Scleroderma Foundation has seen interest in scleroderma grow in all fields. Patients have responded with joy at the realization that there is a place to turn and people who understand. The public is becoming more aware of the disease and willing to support our efforts; and, in the medical community, we have encouraged and watched the tremendous increase in scleroderma research.

As committed members of the Coalition of Patient Advocates we are pleased to include our voice in the request for NIAMS funding in the amount of $224,012. We are gratified that Congress supported three of the six centers requested in 1987 and urge generous consideration of our present request.

The need is urgent--the interest is great. We must not discourage our young investigators who are essential in bringing answers to the problems so prevalent today. To do so puts us all at risk. Lives are at stake; human suffering is at issue.

Thank you for allowing me to speak on these important matters.

STATEMENT OF ALLEN C. LOCKLIN

Mr. Chairman and members of the Committee, I am Allen C. Locklin. I was honored last year to appear before this committee along with members of several other skin groups and wish to thank you for that and the opportunity to again offer testimony for your consideration. I am a geologist and President of a small oil company. My wife and I are co-founders of the National Vitiligo Foundation, Inc., a non profit, charitable foundation formed to find, inform and counsel all Vitiligo patients and their families; to increase public awareness and concern for the patient within the medical community and to encourage, promote and fund increased scientific and clinical research on the cause, treatment and ultimate cure of Vitiligo.

Vitiligo, a non-contagious but hereditary disease is, as you can see from the enclosed color photographs, a disfiguring disorder resulting in pigment loss in the skin, showing as white patches. Except for itching and dryness of the skin and a greater chance for sunburn, there is no physical pain. But, as anyone who is the least bit vain can see, it presents a most disfiguring appearance, leading to extreme psychological and emotional problems for the patients, including suicide. Marriages, jobs and social activities are extremely effected by the occurrence of Vitiligo. Two years ago a young soldier was discharged from the army because of his Vitiligo, as being a socially unaccepted problem. Children in particular are subject to taunts, isolation and being ostracized because of their Vitiligo. Approximately 50% of all the patients have their Vitiligo before age 20.

The Vitiligo patient faces a greater risk of having Hyperthyroidism and Hypothyroidism, Pernicious Anemia, Addison's Disease, Alopecia Areata and Uveitis. It also appears that some connection exists between Vitiligo and melanoma, the deadly form of skin cancer.

Many patients literally withdraw from society, others disquise their problem by wearing long sleeves, high collars, makeup and stains. Basically, each patient wants to be just one color. Vitiligo is not life threatening but it is: "Life Altering".

Vitiligo effects all races equally. It is, however, more apparent in darker skin tones due to the sharp contrast between the white blotches and the pigmented areas. It is estimated that between 1% and 2% of the world's population has Vitiligo, which translates into 2½ and 4½ million Americans having the disease.

As a Vitiligo patient who has suffered the devastating effects of the disease, I have been trying to make a difference in Vitiligo. Our foundation is only 2½ years old, and it is very apparent that the Vitiligo patient has long suffered in silence and they are overjoyed to know someone is trying to help them. I have received letters and phone calls from around the world. We now have contact with over 570 doctors and 24 countries concerned about Vitiligo and anxious to help. These doctors are basically up to date on Vitiligo and its treatment and are eager to learn of new research. We are acting to some degree as a tool and clearing house for them. Currently, we are examining information from other countries, including China, Egypt and Cuba. The Cuban drug Melaginina is receiving attention from around the world with patients eagerly traveling there at great expense to seek a cure. The drug is currently under scrutiny in the USA but is not yet approved for use here.

Unfortunately, many patients with Vitiligo have been told by their doctors to, "Just learn to live with it". This is clearly wrong. There is hope. There are forms of treatment that offer some success for repigmenting. It is time consuming, tedious and expensive, but to some, it is worth it.

For the most part, treatment has only slightly improved over thousands of years. We still rely mainly on the psoralen drugs which were first used by the Egyptians 4000 years ago. You can see that we have not come very far. Research is going on, thanks to this committee, but, it is very limited and much more is needed. Certainly any cuts in funding would be very detrimental to the programs.

Vitiligo falls under the recently designated National Institute of Arthritis and Musculoskeletal and Skin Diseases designated by Congress in 1987. With the exception of some very small individual grants, only the money budgeted to the Consortium of Yale, Massachusetts, Cincinnati and Howard Universities is directed toward Vitiligo research. We support the $224,012,000 level of funding proposed for FY 1989 by the Coalition of Voluntary and Professional Associations Concerned with Programs of the NIAMS from which that money is derived.

We were most gratified by the support Congress gave in 1988 in granting the creation of three of the six core centers for skin disease research requested for FY 1988. It is most important to point out that the cross-over benefits of research can often lead to discoveries that aid patients with diseases other than that being researched. This adds importance to the need for continued funding for research on the many disease problems of the populace.

Once again, I would like to thank this committee for its concern, compassion and support of the many skin disorders you've so patiently evaluated by listening to, reading about and observing the patients and their needs.

Senator WEICKER. Richard, thank you very much for your testimony. I am personally well aware of this situation because my Down syndrome child, Sonny, has just been diagnosed as having alopecia areata.

What about this young man? Eric, is he going to testify?

Eric PESSAR. I have another rare disease. My mom will come next to testify about it.

Senator WEICKER. Oh, OK, great. Thank you all for your testimony. Again, let me assure you that we will do everything possible to enhance the research that applies to the various ailments for which you have spoken so eloquently here this morning. I am very moved by all of your testimony. Thank you very much.

Martha, do you want your picture back? Is this your daughter? She is a lovely young lady.

Now, Eric and his mom will be next, right after this. Or do you want to come up now? Why do you not just wait, let me do this, then you are next. OK?

STATEMENT OF SUZANNE RICHARD, ON BEHALF OF OSTEOGENESIS IMPERFECTA, NATIONAL CAPITOL AREA, INC.

Ms. RICHARD. Senator Weicker, I am a high school junior from Rockville, MD. And I want to thank you for this opportunity to meet with you to present the viewpoint of those affected by osteogenesis imperfecta [OI], the brittle bones disease.

Children with severe OI come into this world with broken bones, some suffered while still in the womb, others occurring during birth. Many of these babies do not survive birth, and many die during the first year.

Those who escape early death may live to experience hundreds of broken bones, sometimes from no greater stress than sneezing, rolling over in bed, or being slightly bumped.

They also face a lifetime of complications, including stunted growth, extreme weakness, corroding teeth, loose joints, hernias, bruising, heat sensitivity, and bone deformities. I have metal rods down both sides of my spine to prevent this.

Those with OI often depend on a wheelchair for mobility, and I myself use one to get around in a crowded high school hall. Other people more mildly affected are able to walk unaided or with crutches.

In some instances they may not even be aware that they have OI until they give birth to a child that is much more severely affected.

It is estimated that there are approximately 30,000 individuals affected by this genetic disorder in the United States alone. That makes it more common than cystic fibrosis, hemophilia, sickle cell anemia, PKU, or tasak.

It is also estimated that about 1 in every 20,000 live born infants is affected with OI, so the numbers keep increasing.

The research that has gone on recently at NIH has ranged from work on rehabilitation, such as leg bracing and growth hormone treatments, which obviously does not work for me, to more basic research connecting tissues, the suspected culprit in the case of OI.

Funds are needed to continue this promising research and to encourage still more research. We have included a summary of our recommendations for funding in a written version of our testimony.

I am here before your committee representing the OI community. In particular I represent osteogenesis imperfecta, National Capital area, and the Osteogenesis Imperfecta Foundation and its members throughout the United States.

But more than that I feel I represent myself, a person who has had about 120 fractures in 17 years. I am very thankful to have benefited from leg braces and therapy that allow me to be quite mobile, as you can see.

I also want to mention two other friends of mine, Katie Astolphe from Massachusetts, who died about a year ago of heart failure after fighting off her many symptoms for all 5 years of her life. I used to visit her every time she came to Children's Hospital for treatment.

And finally I remember my friend, Amy Miller, who died 2 years ago after she fell from her wheelchair. For anyone else the fall would not have been fatal, but Amy had OI. There are other Amys and Katies out there that I know will benefit greatly from the much needed research.

Only a few years ago there was next to nothing being done. Now, because of scientific advances and because for the last several years this committee has shown an interest in OI, progress is being made. Progress in the areas of diagnosis, treatment, and basic research in genetics.

PREPARED STATEMENT

Scientists are interested, and OI families are encouraged. I thank you for listening. Please keep the momentum going by ensuring adequate funding this year and in the future.

Senator **Weicker**. Suzanne, thank you very much for a great presentation. We will keep going. You keep going also.

[The statement follows:]

STATEMENT OF SUZANNE RICHARD

A- INTRODUCTION

Ladies and gentlemen of the Committee, my name is Suzanne Richard and I am a high school junior from Rockville, Maryland. I want to thank you for this opportunity to meet with you to present the viewpoint of those affected by osteogenesis imperfecta, the brittle bone disease.

1. MANIFESTATION

Children with severe O.I. come into the world with broken bones, some suffered while still in the womb, others occuring during birth. Many of these babies do not survive birth, many die during the first year. Those who escape early death may live to experience hundreds of broken bones....sometimes from no greater stress than sneezing, rolling over in bed or being slightly bumped. They also face a lifetime of complications, including stunted growth, deafness, extreme weakness, corroding teeth, loose joints, hernias, bruising, heat sensitivity and bone deformities such as scoliosis....I have metal rods on both sides of my spine to prevent this. Those with O.I.often depend on a wheelchair for mobility. I myself use one to get around in the crowded high school halls.

Other people, more mildly affected, are able to walk unaided or with crutches. In some instances, they may not even be aware that they have O.I. until they give birth to a child that is much more severely affected than they are.

2. PREVALENCE

It is estimated that there are approximately 30000 individuals affected by this genetic disorder in the United States alone. That makes it more common than cystic fibrosis, hemophilia, sickle cell anemia, PKU or Tay-Sachs. It is also estimated that about one in every 20000 live-born infants is affected with O.I., so the numbers keep increasing.

3. COST

The cost of medical care for a person with O.I. is astronomical and it continues throughout his or her lifetime. He or she may need frequent hospitalization, numerous orthopedic and dental procedures, physical therapy, treatment for repeated fractures, special orthopedic equipment such as long-leg braces, crutches wheelchairs and specially-designed seats. When the patients are growing children, appliances need to be replaced frequently and their rehabilitation is therefore costly. Children with cardio-pulmonary complications brought on by O.I. also face frequent hospitalization for respiratory problems, numerous medications and careful monitoring by a physician.

B- RESEARCH IN PROCESS

The research that has gone on recently has ranged from work on rehabilitation, such as leg bracing and growth hormone treatments, to more basic research on collagen and other connective tissues, the suspected culprit in the case of O.I..

1. REHABILITATION

During the last eight years, a rehabilitation program for children with O.I. has been developed at Children's Hospital, National Medical Center in Washington, in conjunction with a bracing program at NIH. It leaves no doubt that most people with O.I. would benefit from a carefully designed and supervised individual rehabilitation program beginning as early in life as possible. However, few physical therapists are, at this point, trained in handling these patients and an educational program for professionals is sorely needed.

2. BASIC RESEARCH

In September, 1987, an International Conference was held in Italy on O.I.. Many of the papers presented reported on work done at the NIH over the past five years.

Among the exciting news were the following items:

- Clear evidence that some types of O.I. are associated with defects in the genes for Type I collagen, the major protein of bone and skin.

- Demonstrated feasibility of prenatal diagnosis for Types II, III and IV of O.I.

- Development of a series of DNA probes (RFLP testing) to determine which Type I collagen is abnormal and whether an individual carries the abnormal gene. - Introduction of a transgenic mouse model with Type II O.I. - New methods for the detection of mutations at the gene level rather than at the collagen protein level.

- AN NICHD researcher has demonstrated that the short stature associated with O.I.is related to deficiencies in either growth hormone or somatomedin-C.

C- FUNDING NEEDS

Funds are needed to continue this promising research and to encourage still more research. It is suggested that the Committee appropriate funds to the NIAMSD for direct research grants for projects with primary emphasis on O.I.. Research in this area would undoubtedly lead to important findings that could be applied to other connective tissue diseases also. I also ask that NIH continue to fund intramural research on O.I. and sponsor research and training fellowship programs for O.I.. Also I ask that NIH issue a request for proposals to study the cardiopulmonary complications that sometimes occur with O.I.. The answers that will ultimately come out of this kind of research will someday help me and all the other children who have been born and are still being born with O.I..

D- SUMMATION

I stand here before your committee representing the O.I. community. In particular, I am am member of Osteogenesis Imperfecta National Capitol Area, a group of O.I. patients, their families and friends from the DC metropolitan area. I also represent the Osteogenesis Imperfecta Foundation and its members throughout the United States.

But more than that, I feel I represent myself, a person who has had about 120 fractures in 17 years. I am very thankful to have benefitted from leg braces and therapy that allow me to be quite mobile as you can see.

I also represent Jay Mandeville from Minneapolis, who has been on oxygen for ten years but still manages to go to school regularly and maintain his interest in sports in spite of the cardiopulmonary complications of O.I..

I also want to mention two other friends of mine, Katie Astolfi, from Massachusetts, who died about a year ago of heart failure after fighting off her many symptoms for all five years of her life. I used to visit her every time she came to Children's Hospital for treatment. And finally, I remember my special friend Amy Miller, who died two years ago after she fell from her wheelchair. For anyone else the fall would not have been fatal, but Amy had O.I..

There are other Amy's and Katie's out there that I know will benefit greatly if the much needed research. Only a few years ago there was next to nothing being done. Now because of scientific advances and because for the last several years, this Committee has shown an interest in O.I., progress is being made.... progress in the areas of diagnosis, treatment and basic research in collagen and genetics. Scientists are interested and O.I. families are encouraged. I thank you for listening. Please keep this momentum going by insuring adequate funding this year and in the future.

E- SUMMARY OF RECOMMENDATIONS

I recommend that the budget for the National Institutes of Health for this year and in the future, include adequate funding for research and education for osteogenesis imperfecta.

Specifically, I recommend:

1- That funds be appropriated to initiate research at the National Institute of Arthritis and Musculoskeletal and Skin Diseases for direct research grants for projects with primary emphasis on O.I. and to support ongoing research at the National Institute of Child Health and Human Development.

2- That NIH continue to fund intramural research on O.I..

3- That NIH sponsor research and training fellowships for O.I..

4- That NIH issue a request for proposal to study the cause and treatment of the cardiopulmonary problems associated with O.I..

STATEMENT OF ARLENE PESSAR, EXECUTIVE DIRECTOR, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA, INC.

ACCOMPANIED BY ERIC PESSAR

Senator WEICKER. All right. Arlene Pessar, are you here with Eric? Good.

Ms. PESSAR. Good morning. It is a pleasure to be here with you today. We are grateful to have this opportunity to thank you for your concern and wonderful support on behalf of all the children and young adults who suffer from epidermolysis bullosa [EB] and other life-threatening and debilitating diseases of the skin.

I am Arlene Pessar. I am the founder and executive director of the Dystrophic Epidermolysis Bullosa Research Association. I also serve on the advisory council of the National Institutes of Arthritis and Musculoskeletal and Skin Diseases. And my son, Eric, was born with epidermolysis bullosa 17 years ago.

This June, Eric will graduate from high school, and plans on attending Polytech University in the fall. Despite the obvious difficulties and challenges he faces, Eric has already beaten the odds.

He has lived substantially longer than the doctors ever predicted, and has accomplished things that even I as his mother was afraid to dream about. Unfortunately, many people with EB are not this lucky.

Even today, many infants and young adults are dying, because of some of the horrible complications associated with EB, such as aggressive skin cancers, overwhelming infections, starvation caused by strictures in the esophagus, and heart failure caused by chronic anemia.

As their parents, we know that without increased support for research, our children face a dreary future with frequent hospitalization and repeated surgeries.

Mr. Weicker, this is the eighth time we have come before this committee. You, Senator Hatfield, and the other Members have listened to us with compassion and understanding. And despite the grim picture I have just painted, there is hope, and progress is being made.

The most exciting news is the establishment of the National EB registry, which was funded last year by the Institute. In a little over a year, approximately 750 patients and families have been entered into the registry and are eagerly waiting and willing to participate in research studies and clinical trials.

We are also very encouraged that the NIAMS will be supporting two core research centers, and hope that additional funds will be provided to establish several others.

Along these lines, we would like to offer our strongest support for the budget recommendations of the NIAMS coalition, and our other colleagues here representing skin diseases today, and urge you to increase appropriations for the National Institute of Arthritis and Musculoskeletal and Skin Diseases to $224 million in fiscal year 1989.

Senator Weicker, I know my time is running out. But before I leave here today there is one other urgent request I need to make. It is time to move the knowledge out of the laboratory.

I understand that this can only be accomplished through a mechanism called specialized centers of research. It is therefore my request that this committee provide funds to establish future specialized centers of research to study EB and other catastrophic skin diseases.

PREPARED STATEMENTS

Your leadership has been incredible, and I know the fight this year is going to be a tough one. But we are depending on your continued support to ensure that our children will live long enough to benefit from the new therapies which only increased funding can bring.

[The statements follow:]

STATEMENT OF ARLENE PESSAR

We are pleased and honored to be here today to share with you about Epidermolysis Bullosa (EB), and we are grateful to have the opportunity to particiate in this important process.

I am Arlene Pessar, founder and executive director of the Dystrophic Epidermolysis Bullosa Research Association of America (D.E.B.R.A.) I am also a member of the Advisory Council of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and serve on the Board of Directors of several other national foundations and groups. Most importantly, I am the parent of a 17-year son with Epidermolysis Bullosa, an incurable and debilitating skin disease.

Epidermolysis Bullosa (EB) is an inherited group of disorders that affects more than 50,000 Americans, mostly children. The morbidity and mortality are high and many patients either die in infancy, or within the first two decades of life. The clinical symptoms range from severe, fatal blistering in the newborn to milder blistering when skin is stressed by pressure, such as walking, mowing the lawn, or typing a letter.

In the severe dystrophic forms, generalized blistering results in loss of body fluids, electrolytes, blood, and proteins through eroded surfaces; dehydration, anemia and growth retardation are frequent complications. Blisters in the mouth and esophagus may interfere with swallowing, and anemia and stunted growth are probably related to nutritional losses. Scar tissue of the nasal passages and larynx make breathing difficult, and blistering of the cornea causes severe pain, and in a few cases, blindness. Continuous blistering leads to scarring that causes disfigurement and deformity of fingers and toes and arms and legs. Eventually patients succumb to overwhelming skin infections or develop aggressive skin cancers in scarred areas.

The medical and surgical costs per patient are enormous and can go as high as $50,000 a year; these expenses are usually not covered by standard health insurance policies and many families are forced to publicize their plight by asking their local church groups and civic organizations to help them meet the cost of mounting medical bills.

D.E.B.R.A. of America, Inc., founded in 1980, is a national not-for-profit organization dedicated to improving the quality of life for all who suffer from EB and other life-threatening and catastrophic diseases. We are committed to changing the dread future for our children, just as our children want to rid their bodies of the painful and ugly sores that cover them, and prevent them from eating, breathing, walking and having fun.

This is the seventh year we have come before this committee, and you, Mr. Chairman, and the other members, have listened to us with compassion and understanding. You heard our cries and have made your recommendations. In 1982, when this Committee first recognized that "epidermolysis bullosa is a life-threatening genetic disease" and directed that funds be used to expand the research programs on EB, exciting progress has been made in our fight against this horrible disease.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is supporting several research projects that will increase the basic understanding of some of the defects in EB and also of the normal structure and function of the skin's basement membrane zone. Other investigators are attempting some of the new skin-grafting techniques and wound dressings, similar to those being used on burn patients, to cover large open areas of skin. And in a little over a year, approximately 750 patients have been enrolled in the National EB Registry, established last year by the NIAMS. In addition to collecting information on the genetics of EB, determine the incidence and prevalence of the disease, the registry will act as an interface between researchers interested in EB and patients willing to participate in various research projects and protocols.

We are also very encouraged and pleased that the NIAMS will be funding two core centers for skin disease research this year. We would like to publicly thank Dr. Lawrence Shulman for his extraordinary leadership in supporting these two centers and hope that additional funds will be provided to establish four more core centers.

Along these lines we would like to offer our strongest support for increased funding for the NIAMS to $224,012,000 for

1989. This level of funding would support the four additional core centers and would allow for an overall increase in the number of research grants approved by the study sections to be funded.

In addition to the creation of basic core centers, we have one more urgent request. Last year the NIAMS funded nine Specialized Centers of Research (SCORs) -- three each in oesteoporosis, rheumatoid arthritis and osteoarthritis. Today, thanks largely to the support of this Committee, the state of science in EB is at a point that would greatly benefit from the concentrated multidisciplinary research approach that bring basic and clinical capabilities together. It is our understanding that this can only be accomplished through the SCOR mechanism.

While it is our firm belief that individual research grants and research training remain at the top of the NIAMS' priorty list, I see a critical need to expand the dermatology centers program. For this reason I respectfully ask this Committee to recommend that NIAMS begin planning for the establishment of a limited number of Specialized Centers of Research. We believe the opportunities for significant advances in EB and other debilitating skin diseases are great enough to justify this new initiative. We also now know there is a large group of patients and families eagerly willing and waiting to particiapate in both basic and clinical research studies.

Mr. Chairman, it would be imprudent if I did not say that we fully recognize the severe budgetary challenges this Committee faces every year. Especially, living in New York, I am keenly aware of the crisis that the AIDS epidemic has caused. But we also know that without additional funding the progress being made in EB will stop, and many more children and adults will suffer and die -- not because of their disease, but because of budget priorities.

We finally know the path that future research in EB must take. As parents, we know we cannot sit back and ask others to help us if we do not help ourselves. But we also know that our efforts alone cannot conquer this disease. We are dependent on your leadership and support to ensure that our children will live long enough to benefit from the new therapies which only increased funding can bring.

Thank you again for giving us this opportunity and for your compassion and concern. The increase in EB research coupled with heightened public awareness has brought new hope into the lives of many patients and families. Your support has made a difference. I urge you to continue to make a difference.

STATEMENT OF DR. NOEL MARKWELL, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION

Good morning. My name is Noel Markwell and I have Epidermolysis Bullosa. I was born and raised in Kentucky. In fact my earliest known ancestor settled in Kentucky shortly after serving as a soldier in the Revolutionary War. I was born in Covington and graduated from public high school in Fort Mitchell. I earned my bachelors degree at Lafayette College and my Ph.D. in Clinical Psychology at Purdue University. After studying and working in Europe I settled in Washington, D.C. in 1962 where I have lived ever since. I worked as a psychologist at D.C. General Hospital for four years and at Georgetown University Law and Medical centers for five years. Since then I have been in private practice and consulting as a licensed psychologist.

Ten years ago I helped found an international professional association, The International Society of Political Psychology, and now serve as treasurer of that organization. Recently I helped found the Institute for Victims of Terrorism, a non-profit organization in which I am an executive officer and director.

From the above you can see that it is possible to live a full and productive life even with EB. However, it has not been easy for my parents or myself and problems associated with EB still plague my life. Also, I have not been able to have children for fear of passing on the disease.

I have had EB since birth though it wasn't accurately diagnosed until two years of age. I have the recessive dystrophic form of Epidermolysis Bullosa, a rather severe form of the disease, but my case is fairly mild. My hands and feet are most affected. Rarely during my life have I been without sores on my feet or hands. The illness was worse as a child when I was more physically active and got injured a lot. Many pictures of me as a child show me with bandages on my hands, elbows and knees. Emotionally I had to deal with the pressure of being different from other children; not being able to do things -- sports, or going away to camp. But I attended an excellent public school in Fort Mitchell, Beechwood School, and excelled in other ways; was well thought of by my classmates and, in fact, was elected president of my senior class.

But EB does not get better as you grow older -- but you learn to live with it. My largest problem now is strictures in the esophagus. I have always had trouble swallowing but in the past ten years it has gotten progressively worse. Just earlier this month I had to go to George Washington University Hospital Emergency Room to get intravenous fluids after eight days of not getting down anything, including water or saliva.

I grew up in the "dark ages" period of EB when we lived without knowledge about the disorder. As a college and graduate student I had an intense desire to learn as much as I could about my disease. I visited many outstanding medical centers - Hahnemann in Philadelphia; Johns Hopkins; New York University; Mayo Clinic; Karolinska in Stockholm; Guys Hospital in London -- all seeking answers but there were none. Very few of the specialists had ever seen a case before. There was only the knowledge they had from text books written years before. There was nothing new or hopeful - because no one was studying it.

Only in the past ten years - since D.E.B.R.A., and since the NIH have funded research - has real hope emerged for diagnosis of new cases, genetic information, and help in handling the other effects of this disorder.

I have attended two conferences sponsored by D.E.B.R.A. and the NIH -- one in 1981 on the scientific studies related to EB and outlining the specific disease mechanisms involved in the disease. The other meeting focused on the non-dermatological aspects and clinical management of patients and brought together many new ideas for improving the quality of life for EB patients.

I learned new techniques for wound healing that have had remarkable effects on healing lesions on particular areas of my feet that had been raw, infected, and unhealing for more than two years. I have, at least, three times donated pieces of skin for research studies done through NIH, and now with the new EB registry many other EB patients will have the opportunity to participate in such research efforts.

What has been accomplished in the past few years has been impressive. This has been a period of real hope and enthusiasm for all EB patients and their families. We thank the NIH and the other medical centers involved in the research efforts for the wonderful advances that have been made. But ultimately, the thanks goes to you and other members of Congress who have provided the funds for this research.

We are thankful for your continued concern and interest and hope that the level of funding can remain high so that the momentum and the hope can continue.

Senator WEICKER. Arlene, thank you very much for your testimony. I know Senator Hatfield has just come in here, who has been one of the most eloquent advocates. I see a big smile on Eric's face.

Just before Senator Hatfield takes over, Eric, when do you graduate from high school?

ERIC. June 14.

Senator WEICKER. June 14. That is just great. You can be very proud.

I see Senator Chiles, the chairman, has arrived. Senator Hatfield has arrived. And I know Senator Hatfield's particular interest. So I will now yield to him, and then to the chairman. Nice to have you all here.

Senator HATFIELD. Thank you, Mr. Chairman. I would like to join the chairman, the acting chairman and the full committee chairman, today in welcoming you folks here to testify on this very important part of our medical research.

Congratulations, Eric, too. I want to add my voice to congratulating you on being college-bound. I understand that you have a scholarship for your college work. Not yet? I see. And you want to study engineering?

Well, I am very, very pleased to know that. And Arlene Pessar, I want to thank you again for your pioneering work in developing a public awareness as well as the lobbying effort that you have organized to develop this.

How many years ago that we were not spending any money at all in——

Ms. PESSAR. Six. A short time ago.

Senator HATFIELD. That short a time. Well, a great deal of that credit goes to you and to the effort that you have made.

I have no questions, Mr. Chairman. I just wanted to be here today to welcome not only the testimony of Arlene Pessar, but I wanted to congratulate Eric. And I also would like to say to Mr. Will Wachtel of Portland, OR, that, while I missed his oral testimony, I will be reading the testimony and giving support to the cause that he represented. Thank you.

Senator CHILES [presiding]. Thank you, Senator Hatfield. And we well remember that it was work that you did in this subcommittee that started this funding, and we thank you for that, and all of the interest you have shown.

You have long been a member of this subcommittee, but when you were chairman of the full committee you always paid particular attention and help to this subcommittee. And we thank you for that interest.

And we again congratulate you, Eric. That is terrific. And we thank you all for your diligent work and efforts in this regard. Thank you very much.

STATEMENT OF DR. PEYTON E. WEARY, ON BEHALF OF THE AMERICAN ACADEMY OF DERMATOLOGY, AND THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

Senator CHILES. Now we will hear from Dr. Peyton Weary of the American Academy of Dermatology.

Dr. WEARY. If I may, sir, I would like to have this testimony placed in the record.

Senator CHILES. All right, sir. We will put those in as part of your testimony.

Dr. WEARY. Senator Chiles, Senator Hatfield, I am very pleased to be here today to present testimony on behalf of the American Academy of Dermatology and the Society for Investigative Dermatology.

Much of what I have to say has been already said by the coalition members from the skin disease group here. But I would like to repeat it for those who were not here at the time, because I think I have a very important message for you today.

The message really is very simple, and it is demonstrated on these two graphs that I am showing you here, which indicate that the National Institute for Arthritis and Musculoskeletal and Skin Disease is severely underfunded.

It is underfunded to the point where, at the present time, the award rates, which you see here, the lower line being the National Institute for Arthritis and Musculoskeletal and Skin Disease, the upper line being for the NIH overall, shows that there is a significant disparity between the award rates for approved grants between this Institute and the rest of the NIH.

In fact, the grants for the rest of the NIH that are approved are being funded at a level of 1 out of 3, whereas the grants for this Institute are being funded only at a level of 1 out of 4.

This disparity is very disturbing to us. This is not a reflection, however, of the fact that the grant applications are deficient in this Institute, because if you look at the other graph on my right you will find that the pay lines actually are lower for the NIAMS than they are for the rest of the Institutes overall, which indicates, as you know, that the lower the pay line the better the grants.

So what we feel is that this is a self-perpetuating problem, and it has been in existence ever since this new Institute was broken away from the previous Institute. We think that this self-perpetuating problem needs to be corrected very much, because it is very demoralizing to the people doing research in this area.

Senator CHILES. Are you saying that it was a mistake to break it away?

Dr. WEARY. I do not think it was a mistake to break it away, but I think that the initial funding levels were not appropriate and not adequate at the outset.

And I think that, we are not saying that every Institute should have parity with every other Institute, because I think that is unrealistic. But to start off at a significant disadvantage as this Institute did, I think that is the problem. And we think that that should be corrected, if possible.

The figure that we are recommending is a minimum increase of $17 million, which would be necessary to establish parity between this Institute and the other Institutes at the NIH, on the average. And this is what we are requesting this year at a minimum.

PREPARED STATEMENT

Now, we have requested significantly higher figures in the testimony that I submitted, realizing that there are other needs too. But certainly the $17 million figure, over and above the President's approved budget, would be a minimum, we think, to establish the parity that is so necessary. Thank you very much.

Senator CHILES. We thank you for your testimony. We will certainly look at it carefully.

[The statement follows:]

STATEMENT OF DR. PEYTON E. WEARY

Mr. Chairman, I am Peyton E. Weary, M.D., Professor and Chairman of the Department of Dermatology at the University of Virginia School of Medicine and Washington Representative from the Council on Governmental Liaison of the American Academy of Dermatology. I am also a past Vice-President of the Society for Investigative Dermatology. I am presenting this testimony on behalf of the American Academy of Dermatology, whose membership of over 6,500 represents the majority of American dermatologists, and on behalf of The Society of Investigative Dermatology, the representative organization for the dermatologic biomedical research community.

I am pleased to report once again that there have been many exciting advances in our basic understanding of a number of skin diseases in the past year. There are also many promising avenues of research that remain to be explored and there are many opportunities for improved patient care through research. Among the more promising areas of research, I would particularly cite our increasing knowledge of the skin as a vital link in the immune system and, in particular, the role of the Langerhans Cell of the skin in this process and its possible involvement in the disease, AIDS. We are also increasingly aware of the importance of the wart virus not only as a cause for benign, and occasionally malignant, skin lesions but as an initiator of cancer of the cervix in women. Furthermore, at a molecular biology level, our increasing sophistication in understanding the composition and interactions of tissue proteins such as keratin and collagen, which are basic building blocks of the skin, portend a host of other advances.

We were gratified to note that the Congress supported the creation of three of the six core centers for skin disease research which we requested last year. We are also pleased to report that, even with the tight budgetary restrictions, at least two of these centers will be funded this year. We understand that a number of proposals have already been submitted by excellent institutions.

However, Mr. Chairman, I come to you today with a very important message. This message is that the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is significantly underfunded and thus unable to fulfill the mission for which it was expressly created which was to provide increased emphasis on research in the disabling and crippling disorders represented by the disciplines therein.

If we look at the NIAMS in comparison to the overall NIH experience only in terms of two parameters we immediately perceive a highly significant disproportion as follows:

1. Paylines

The paylines for NIAMS when compared with the average paylines for the NIH as a whole show the following significant disproportion:

Year	NIAMS	N.I.H.
1986	155	171
1987	147	174
1988 (est.)	140	160

Furthermore, the NIAMS has the lowest paylines of any institute at the NIH.

If the peer review process is to work as it should to ensure that the best research is supported across the board it is not reasonable to permit such significant disproportions in paylines to become self-perpetuating as it would appear is the case. To restore a proper balance will require additional support for the NIAMS over and above a cost-of-living increase.

2. Award Rates

If we look at the award rates for approved grants we find the same disequilibrium:

Year	NIAMS	N.I.H.
1986	33.1%	36.0%
1987	30.8%	38.3%
1988 (est.)	25.2%	33.8%

Again the NIAMS has the lowest award rate of any NIH institute. It is most disheartening to both established and young investigators alike to relize that only one of four grants submitted to the NIAMS which are approved are currently being funded. Should this inadequate reward system become firmly established, we would predict a drastic dimunition in the esprit de corps and enthusiasm of our young investigators, an enthusiasm that has characterized the revolution in skin research in the past two decades.

Furthermore, to maintain even this inadequate level of award rates it has been necessary to impose across the board percentage cuts in the amount of each grant yearly since 1986 as follows:

Year	% Cut in Grant
1986	13%
1987	8%
1988 (est.)	12-13%

We would also note that the average size of the individual grants requested for funding by the NIAMS remain within the lower levels of grant size for NIH as follows:

Year	Average NIAMS Grant Request
1986	$136,000
1987	$159,000
1988 (est.)	$159,000

It is for the above reasons that the Coalition of Voluntary and Professional Associations Concerned with Programs of the NIAMS have proposed a substantial increase in funding and would recommend the appropriation of $224,012,000 for 1989 for this terribly underfunded institute and we urge that you give serious consideration to an increase of this magnitude. Such a level of funding would facilitate the establishment of parity for the NIAMS in comparison with the other NIH institutes and would allow the fulfillment of the other commitments to support the centers and the training of young investigators so essential to the mission of the NIAMS.

As in the past, Mr. Chairman, the American Academy of Dermatology and the Society for Investigative Dermatology also wish to present testimony on behalf of some of the other institutes at the NIH and also for NIOSH all of which support skin-related research.

We are particularly anxious to encourage increased support within the National Cancer Institute for research in malignant melanoma and other skin cancers which are increasing at an exponential rate in our society and could increase even more if the ozone layer depletion cannot be stopped. Such research is necessary to supplement and enhance the significant efforts of the dermatologic community to create a comprehensive, coordinated and sustained National Program for the Prevention and Early Detection of Melanoma and other Skin Cancers. We would urge a special emphasis on the part of the NCI for such research and encourage the NCI to provide an ongoing commitment to prevention and early detection of these skin cancers.

Because a large number of skin diseases are either infectious or immunological and because one of the major sites for manifestation of AIDS is the skin, we have a particular affinity for the National Institute of Allergy and Infectious Diseases and we encourage strong support for this institute.

We also are aware of the need to provide more effective therapy for skin problems of the elderly and the need for the National Institute on Aging to encourage and support more research into the aging process in the skin. The effects of the derivatives of vitamin A (retinoids) upon the skin as a way to reverse some of the sun-induced and age related changes offers a unique new opportunity to study the process of aging of the skin and such studies need to be pursued vigorously.

Finally, because so many problems with the skin are related to external factors such as sunlight, the ozone layer depletion, nemerous chemicals, climatic factors and trauma in the environment and the workplace, we would urge strong support for both the National Institute of Environmental Health Sciences and the National Institute for Occupational Safety and Health and, in particular, the latter which has for years been woefully underfunded in comparison to the urgent need for research in occupational illness which causes so much disability and loss of productivity.

Thank you for the opportunity to share our concerns with you today.

FACT SHEET

The NIAMS is severely underfunded and the problem appears to be self-perpetuating. The following data support that statement of fact:

1. Paylines: The paylines for NIAMS, when compared with the average paylines for the NIH as a whole, show the following significant disproportion:

Year	NIAMS	N.I.H.
1986	155	171
1987	147	174
1988 (est.)	140	160

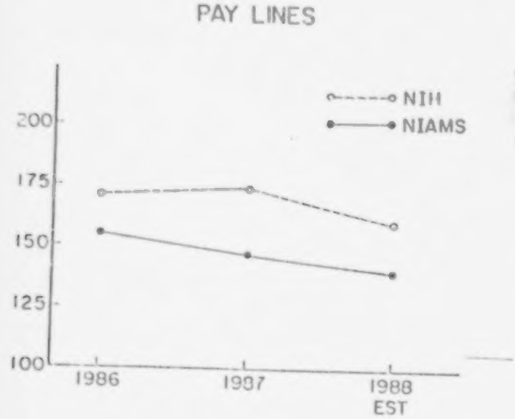
Furthermore, the NIAMS has the lowest paylines of any institute a[illegible] the NIH. Since the lower the payline the better the quality of the grant, it is apparent that grants of lesser quality are being supported in other institutes in comparison to the grants supported at the NIAMS.

2. Award Rates: If we look at the award rates for approved grants we find the same disequilibrium:

Year	NIAMS	N.I.H.
1986	33.1%	36.0%
1987	30.8%	38.3%
1988 (est.)	25.2%	33.8%

Again the NIAMS has the lowest award rate of any NIH institute. Thus, while one of three approved grants elsewhere in the NIH is funded, in the NIAMS, only one of four approved grants is funded. This inequity is demoralizing to investigators in our field and such a disequilibrium undermines the purpose of the peer review process.

To restore parity, the NIAMS must receive more than a cost of living increase. The American Academy of Dermatology, the Society for Investigative Dermatology, the Society for Investigative Dermatology and the Coalition of Patient Advocates for Skin Disease Research all support the recommendation of the Coalition of Voluntary and Professional Associations Concerned with Programs of the NIAMS for a FY 1989 appropriation figure of $224,012,000 for the NIAMS. This amount would allow the approved centers to be funded as well.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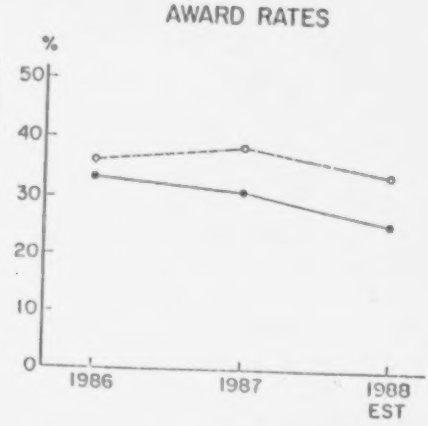
AWARD RATES

STATEMENT OF DR. THEODORE L. MUNSAT, ON BEHALF OF THE AMERICAN ACADEMY OF NEUROLOGY

Senator CHILES. Now we will hear from Dr. Munsat, the American Academy of Neurology.

Dr. MUNSAT. Senator Chiles and members of the committee, my name is Dr. Theodore Munsat. I am a neurologist at Tufts University in Boston and president of the American Academy of Neurology, which represents 10,000 neurologists and neuroscientists.

I am pleased to have the opportunity to advise you of our strong support for increased funding levels for fiscal year 1989 for the NIH and particularly for the National Institute of Neurological and Communicative Diseases and Stroke, the NINCDS.

This Institute has, within its broad mandate, some 600 different disorders, such as epilepsy, stroke, and muscular dystrophy. The economic costs of these diseases have been estimated at $114 billion yearly.

Today, NINCDS is the Nation's largest research organization supporting and conducting research aimed at furthering the understanding of the normal and the disordered brain.

We in the neurosciences firmly believe that the next decade holds the possibility of more successful treatments and cures for many neurologic diseases. Thanks to your continuing leadership, and thanks to Senator Weicker, and with the support of Senators Domenici and Riegle and others, a resolution declaring the next 10 years the decade of the brain has been introduced.

The Academy of Neurology enthusiastically supports this legislation as an indication of the importance of brain sciences. The field of neurogenetics, for example, has exploded.

A recent identification of the gene for the most common form of muscular dystrophy and isolation of the missing protein prepares us to begin effective therapies based on more meaningful scientific information, if funding is provided.

Further, these advances can be employed to foster similar breakthroughs for other inherited diseases, such as Huntington's disease and certain forms of Alzheimer's disease, and Lou Gehrig's disease. This can be accomplished only with adequate monetary support.

Today the entire NINCDS research budget is less than 1 percent of the amount which is being expended to treat people with these diseases.

For the current fiscal year, NINCDS estimates that it will be able to fund less than one-third of approved new budget grants. Under the President's request for fiscal year 1989, the prospect would be not much brighter. Funding well above the President's request of $557.6 million must be provided.

We heartily endorse the Institute's efforts relating to the neurologic consequences of AIDS. A majority of AIDS patients exhibit neurologic and behavioral difficulty.

Mr. Chairman, we believe that $704.5 million is needed to foster growth in these important research areas. I realize that this represents a quantum increase. But we in the brain sciences believe that this is appropriate, as we are truly about to enter the decade of the brain.

PREPARED STATEMENT

Thank you very much for your most generous support in past years. The Academy of Neurology respectfully urges you to take all the necessary steps to ensure our recommended funding levels. Thank you very much.

[The statement follows:]

STATEMENT OF DR. THEODORE L. MUNSAT

I am Dr. Theodore L. Munsat. I am a neurologist at Tufts New England Medical Center and President of the American Academy of Neurology. The Academy is a professional organization representing 9700 neurologists in the United States and world-wide. I am pleased to have the opportunity to be with you today to advise you of our support for increased funding levels for FY '89 for the National Institutes of Health, particularly the National Institute of Neurological and Communicative Diseases and Stroke (NINCDS).

Overall Funding Concerns (NIH)

The NIH is the world's finest biomedical research complex. The continued vitality of the NIH research enterprise is a crucial component of national efforts to improve the health and quality of life of all Americans. The AAN joins with numerous professional organizations and voluntary health groups in advocating funding for NIH at $8.47 billion for FY '89. At $6.6 billion, the President's request for FY '89 is not even sufficient to maintain programs at their current levels, in light of the rising costs of conducting research today. These growing costs are inherent to modern research; for example, state of the art techniques require more expensive materials, more sophisticated equipment and may demand more highly-trained staff. These requirements do not even take into account general inflation.

The Academy believes that our recommended funding level will be sufficient to maintain the current momentum of biomedical research at NIH, and to foster modest expansion in promising new areas. Our funding recommendation of $8.47 billion for NIH would be adequate to accommodate an award rate of 41 percent for investigator-initiated research project grants, and would at the same time allow for appropriate increases in other critical funding mechanisms, including research training and NIH's intramural programs. Ultimately, sufficient funding should be afforded to allow the Institute to support approximately half of all approved research projects--the entire range of which consists of extremely valuable research.

For quite some time research training has been an area of concern to the Academy. Individual and institutional training awards provide crucial support to young investigators seeking full time careers in research and/or teaching. The AAN agrees that funding sufficient to increase the number of trainees consistent with the level recommended by the Institute of Medicine of the National Academy of Sciences should be afforded. Mr. Chairman, we are convinced that increased support for research training activities is absolutely essential if we are to expect to continue to be able to attract the brightest students into the study of medicine.

NINCDS Research Activities

The National Institute of Neurological and Communicative Diseases and Stroke, (NINCDS) has within its broad mandate, some 600 different neurological and communicative disorders. The economic costs alone which are associated with these disorders have been estimated at $114 billion each year. The costs in human pain and suffering are much greater.

Today, NINCDS is the nations largest research organization supporting and conducting research aimed at furthering the understanding of the normal and disordered function of the nervous system, (including the brain, the spinal cord, and peripheral nerves). Neurological disorders are numerous and varied. Some are among the leading causes of death; but others are characterized primarily by long term disabilities which markedly impair the quality of life.

Neurological diseases strike people across the spectrum of age. Diseases which strike people at an early age include spina bifida, cerebral palsy and muscular dystrophy; disorders of youth and early adulthood include epilepsy, head and spinal cord injuries and multiple sclerosis; conditions of later adult life and the elderly include Huntington's disease, Parkinson's disease and dementias such as Alzheimzer's disease. While a considerable portion of the institute's initiatives have focused on the fundamental workings of the nervous system, clinical studies continue to be conducted aimed directly at the development of improved methods for prevention and better opportunities for improved diagnostic and therapeutic methodologies for these diseases.

The field of genetics has begun to provide some important discoveries, including markers, links, and tests for genetic disorders of the nervous system. Among the brain disorders for which scientists have new information are Huntington's disease, and Duchenne muscular dystrophy. Work is proceeding to validate genetic markers for the two separate but somewhat similar disorders known as neurofibromatosis-1 and neurofibromatosis-2, which will ultimately make possible prenatal diagnosis and accurate genetic counseling. Further research is leading to the isolation of genes of other neurological diseases, such as Alzheimer's disease, and to the discovery of the nature of the biochemical defects that these genes control.

In addition, NINCDS is continuing its efforts to alleviate the personal tragedy and national burden of head and spinal cord injuries which, together affect an estimated 400 to 500 thousand Americans each year. Five NINCDS-sponsored spinal cord research centers are conducting research to enhance our understanding of the events that happen in the interval between spinal injury and the death of nerve cells--an interval that may last as long as 24 hours. The possibility of effective treatments in the prevention or amelioration of paralysis during this "window" are being explored.

Traditionally, scientists believed that damaged nerve cells in the brain are incapable of regeneration. However, recent work shows that under special laboratory conditions damaged nerve cells may be able to function again. Researchers have demonstrated that nerve cells from the central nervous systems of mammals can sprout new branches when they are in contact with supporting cells associated with skin and muscle nerves. Whether these indications that adult brain cells can have the capacity for growth can be used to actually repair the injured brain -- with its billions of nerve cell connections--is a subject of on-going research.

The medical, social, and economic impact of head and spinal cord injuries are enormous, with specialized long-term care for paralysis patients costing society approximately $2 billion each year. Vigorous intensive care monitoring and early treatment of organic and biochemical dysfunction in patients with head injury have led to improved survival but not necessarily to more rewarding lives for these individuals. Today's research challenge includes achieving a better understanding of the mechanisms that can promote improved survival, and of the biochemical properties that can lead to improved cerebral function.

NINCDS Funding Recommendation

Today, the entire NINCDS research budget is less than 1% of the amount which is being expended to treat people with neurological and communicative disorders. For the current fiscal year (FY 88), NINCDS estimates that it will be able to fund about 33% of approved new project grants. We are confident that funding well above the President's request of $557.6 million must be afforded if this rate is to be brought up to an acceptable level, while at the same time accomodating modest growth in other important mechanisms such as training, centers and the NINCDS intramural program. We have determined that funding for FY 89 in the amount of $704.5 million is the minimum needed to foster growth in the important research areas we have mentioned here today.

Conclusion

In past years the committee has seen fit to provide funding levels well above the Administrations requests for both NIH and for NINCDS. Mr. Chairman, today we thank you for your past efforts and urge your continued commitment toward achieving funding levels sufficient to support the important research efforts of the NINCDS.

In January of this year the National Advisory Neurological and Communicative Disorders and Stroke (NANCDS) Council issued a report on priorities in the neurosciences. The Council termed this concept the forthcoming "Decade of the Brain". Soon afterward, a joint resolution on the "Decade of the Brain" was introduced in both houses of Congress. Under the continuing leadership of Senator Lowell Weicker, Jr. and with the support of Senators Domenici, Riegle, and others, the Academy is optimistic about this legislation, and the prospect of a vigorous effort to ensure that research opportunities in the neurosciences are fully exploited in the immediate future.

The Academy heartily endorses a comprehensive national effort focused on nervous system research and clinical methodologies: The substantial reductions in the human and economic costs of neurological diseases must not be left outside our reach.

The AAN respectfully urges you to take all necessary steps to ensure that our recommended funding levels of $8.47 billion for NIH and $704.5 million for NINCDS are enacted. The Academy stands ready to serve as a resource as determinations are made.

Senator CHILES. Thank you very much, Doctor. We appreciate your testimony. And now we will hear from Rosalyn Davis and Audrey Thomas of the Reflex Sympathetic Dystrophy Syndrome Association.

Ms. DAVIS. I want to thank you for giving us the opportunity to testify before your committee today, and I would also like to introduce to you Dr. Nelson Henler, the Director of Medical Research, and he will give our testimony.

Thank you very much, gentlemen.

STATEMENT OF DR. NELSON HENLER, CLINICAL DIRECTOR, MENSAWNA CLINIC, ASSISTANT PROFESSOR OF NEUROSURGERY, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE, AND ASSOCIATE PROFESSOR OF PHYSIOLOGY, UNIVERSITY OF MARYLAND DENTAL SCHOOL, ON BEHALF OF REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION

Dr. HENLER. Thank you, Senator Chiles. It is a pleasure to be here. We represent the Reflex Sympathetic Dystrophy Association of the United States. I am Nelson Henler. I am clinical director of Mensawna Clinic, assistant professor of neurosurgery, Johns Hopkins University School of Medicine and associate professor of physiology, Unversity of Maryland Dental School.

I have given you some reviews of books that I have written about chronic pain.

Reflex sympathetic dystrophy is a most disabling disorder best described as a constant burning pain that eventually causes the decay and erosion of bone and can lead to pathological fractures. Most of the patients with this disorder lead a life of horrible, unremitting, constant pain best described as holding a limb over a burning fire constantly.

This leads to a great degree of disability. The number of patients that suffer from this disorder has been estimated between 5 million to 10 million patients within the United States. Unfortunately, many physicians do not recognize the existence of this disorder and very often misdiagnose it as psychogenic in origin. The article that I have given you talks about three such nurses who were committed to psychiatric hospitals, mistakenly with the diagnosis of psychogenic pain, who were later diagnosed as having reflex sympathetic dystrophy.

In the past year only $66,000 was devoted toward research from the NINCDS. However, this disorder is crippling, disabling. Forty percent of the people with the disorder are under the age of 30, many of whom wind up with permanent disabilities and become a great burden and a financial drain on the Federal Government since they are being supported by Social Security disability payments and other forms of government support.

We would like to increase physician awareness; we would like to provide physician education, patient awareness, and basic science research, and we respectfully request an increase in funding from zero to $5 million.

Thank you very much, Senator.

[The statement follows:]

STATEMENT OF DR. NELSON HENLER

Reflex Sympathetic Dystrophy Syndrome (RSDS) is a multi-symptom, multi- system disease, usually seen in an extremity, but may affect any area of the body. A variety of symptoms may be present, the only common one being chronic pain, usually burning in nature. Because this condition often goes undiagnosed, it is considered to be rare. However, after obtaining estimates of the prevalence from several physicians involved in the treatment of this disorder, it is evident that RSDS/Sympathetically Maintained Pain (SMP) is not a rare disorder. John J. Bonica, M.D., founder of the American Pain Society and the International Society for the Study of Pain, and world renowned in his field, states that of his estimate of 60-70 million Americans that suffer from all types of chronic pain, 10% is a reasonable estimate of those afflicted with RSDS/SMP. Gabor Racz, M.D. at Texas Tech and his colleagues estimate there to be 24 million Americans suffering from all types of chronic pain. Dr. Racz estimates that 17.5% have RSDS. Using estimates of the average number of patients with RSDS/SMP from 17 physicians and pain centers in the United States and an average of the total population with chronic pain, our mean average of chronic pain patients with RSDS/SMP is 22.2% or an estimated potential of 9.8 million people afflicted with RSDS/SMP whose average age is 35.8 years. Without early diagnosis and proper management, those afflicted with this disorder are relegated to a life of intractable pain and permanent disability. We therefore request that funds be specifically allocated for education and research.

Following are additional remarks about the incidence of Reflex Sympathetic Dystrophy Syndrome (RSDS) and Sympathetically Maintained Pain (SMP), from several noted physicians in this field:

John J. Bonica, M.D.,DSc., Anesthesiologist at the University of Washington, Seattle, WA, states that of the 60 to 70 million people suffering from chronic pain, approximately 10% have RSDS and SMP.

Arthur Ecker, M.D., Neurologist, Syracuse, NY, states: "In the past six years, with modern diagnostic methods (especially thermography), in the private practice of Neurology, among 345 patients with obscure pain, I was able to diagnose 144 cases of reflex sympathetic dystrophy. Obviously, it is a much more frequent condition than had previously been believed."

Felix Fernandes, M.D., Anesthesiologist at the University of Wisconsin Medical School states: "I am an anesthesiologist and work in the Multidisciplinary Pain Clinic at the University of Wisconsin Hospital in Madison, Wisconsin. We saw about 1200 new patients in the Pain Clinic from January - December 1987, and I would estimate that between 5-8% of those patients had reflex sympathetic dystrophy/sympathetic maintained pain."

John P.F. Ingall, M.D., Medical Director, Gertrude Levin Pain Clinic, Detroit, Michigan, states: " As Director of this clinic, one sees many pain conditions and has over the years become impressed by the frequency of a condition which suffers with the title of 'reflex sympathetic dystrophy.'"

Perry G. Fine, M.D., Anesthesiologist at The University of Utah, Salt Lake City, Utah, following a telephone conversation with us states: "Of the 270 new patients and 1395 follow-up patients that we have seen in the last year, approximately 10% would be considered to have some component of sympathetically mediated pain contributing to their persistent pain syndrome. The youngest patient referred to us has been 8 years of age with this type of problem and the oldest have been in their 80's. The average age of our patient population that we treat for this problem is in the 35-45 year old age group."

Richard S. Weiner, Ph.D., at The Institute of Pain Management, Ceres, California, states: "At the Insitute of Pain Management, a multidisciplinary nonprofit pain clinic located in Central California, we see many individuals who suffer from Reflex Sympathetic Dystrophy. The prevalence in our practice is approximately 10 percent."

Gabor Racz, M.D., Anesthesiologist at Texas Tech University, Lubbock, Texas, states that 15% to 20% of his patient population have classic RSDS with burning pain. He also states that 70% of all patients he treats have Sympathetically Maintained Pain. The average age of his RSDS population is 35 years old.

Reza R. Azar, M.D., Anesthesiologist at the Pain Rehabilitation Center, Doylestown, PA, states that 8% of his total population of patients have classic RSDS and 37% have Sympathetically Maintained Pain. The average age of onset is 30-35 years old.

Terri Dallas, M.D., Anesthesiologist at the University of Chicago, Chicago, Illinois, states that 36.8% of her patients have RSDS. The average of onset is 31.2 years old.

Toni McClellan, M.D., Neurologist, Colorado Springs, Colorado, states that 11.5% of her neurology practice have RSDS/ Sympathetically Maintained Pain. The average age of onset is 35 years old.

Walter Olsen, M.D., Neurologist, Maumee, Ohio, states that 12% of his neurology practice have RSDS/Sympathetically Maintained Pain, with the average age of onset at 30-35 years old.

Bernard Edwards, M.D., Anesthesiologist, South Bend, Indiana, states that 15% of his patients have RSDS. Average age of onset is 35-39 years old.

David Zohn, M.D., Physical Medicine and Rehabilitation, Falls Church, Virginia, states that 23% of his patients have RSDS, with average age of onset at 50.3 years old.

Bernard Filner, M.D., Anesthesiologist, Rockville, MD, states that 15-25% of case referrals have RSDS. Average age of onset is 35 years old.

Beverly Zelt, M.D., Anesthesiologist, Petoskey, Michigan, states that 50% of her patient population have RSDS/Sympathetically Maintained Pain, with the average age of onset at 35 years old.

The Pain Control Center at Loma Linda, California, reports 25% of their patient population have RSDS/ Sympathetically Maintained Pain, age range between 20 and 40 years old.

Robert J. Schwartzman, M.D. and Robert L. Knobler, M.D. Neurologists at Thomas Jefferson University Hospital, Philadelphia, Pennsylvania, state that 21% of their patient population have RSDS/SMP.

Senator CHILES. We thank you very much, and we appreciate your testimony.

Ms. Davis Thank you.

STATEMENT OF MAUREEN DRUMMY, MEMBER, NATIONAL ARTHRITIS ADVISORY BOARD

Senator CHILES. Now we will hear from Maureen Drummy, the National Arthritis Advisory Board.

Ms. DRUMMY. Hello, Chairman.

I was able to walk to this table entirely through your efforts, and I am here mainly to thank you. I am also here as a member of the National Arthritis Advisory Board.

As you know, your committee started focusing on arthritis with the passage of the National Arthritis Act in 1975. I had arthritis for 13 years before 1975, and I cannot begin to tell you how much difference you have made in one decade.

In the sixties, when I was in my twenties, it took physicians more than a year to realize that my swollen knee was not a sports type injury. My knee was aspirated five times, it was placed in plaster casts, was operated on by Mickey Mantle's surgeon, and still I could only get around with crutches.

In the seventies, while I was working for an ever-understanding Congressman, William Steiger of Wisconsin, I had several disabling flareups. One day in 1977 they carried me out of the Longworth Building and a team of rheumatologists urged me to apply for disability and give up my job on Capitol Hill.

Luckily, at that very moment research was beginning to pay dividends in the form of perfected joint replacements. I was literally reviewing the forms for disability when suddenly you were like the cavalry coming over the hill to my rescue. I received the first artificial hip in the United States that was implanted without cement. Cemented hips were lasting only about 8 years, and I was told that this one might or might not last longer. I am pleased to report that it is 11 years old, and it is still working and I am still working.

I have two artificial knees, a second hip and a reinforced wrist. And today more than 100,000 joint surgeries are performed each year. Had we not had the benefit of your research, and had I gone on disability in 1977, I alone would have cost the U.S. Treasury $180,000 by the end of last month. Instead, I have paid $70,000 in taxes. More important to me than this sum of $250,000 in the cost effective nature of your investment, members of your committee have improved my life beyond measure.

I am honored to present to you the recommendations of the National Arthritis Advisory Board. With your permission, I would like my writen statement to be made part of the record, and I would like to focus on the request for research dollars, as some of the others have.

The scientists are convinced that we are on the threshold of breakthroughs in arthritis, and indeed, NIH supported research has already found the cause and cure for one form, which is Lyme disease. As you may know, it was Lyme disease that forced Congressman Berkley Bedell to give up his seat in Congress.

The young rheumatologist who was doing so much to control Lyme disease, Dr. Allen Steere of the New England Medical Center, is a member of our board. I was in the room this January when I overheard Dr. Shulman tell Dr. Steere that this year's budget cut requires that his project be cut by $24,000, or 12 percent, and that he is among the lucky ones, because only 25 percent of our institute's approved applications can be funded.

And here we have one of the star young scientists of the world who just recently was honored in Australia, and in the softest voice he said, "that is devastating." We are losing people who could make a real difference. I just thought I would share that with you.

There are vast numbers of people who have our diseases, and I would like to compare it with the Postal Service with its 40,000 offices and 800,000 employees. Last year that cost $37 billion, and experts say by comparison, arthritis costs us $31 billion plus $25 billion in lost earnings. So clearly the problem is staggering.

I want to thank you for everything you have done, and hope that you will continue to do so.

PREPARED STATEMENT

In closing, I know you are retiring this year, Mr. Chairman, and I cannot leave without a word saluting you and your work. I hope you will also pass on a parting word to Senator Proxmire. I think he is a legend, I am a Wisconsinite, and I hope his example is emulated for years to come

Thank you.

[The statement follows:]

STATEMENT OF MAUREEN DRUMMY

I am Maureen Drummy, a member of the National Arthritis Advisory Board (NAAB). I am honored to have the opportunity to appear before you this year to testify in support of the FY 1989 budget for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

About one in three Americans has or will suffer from some form of arthritis, musculoskeletal, or skin disease. These disorders include such diverse states as rheumatoid arthritis, osteoarthritis, osteoporosis, low back pain, fractures, sports injuries, and skin diseases such as scleroderma and psoriasis. Many of these disorders last a lifetime. Some are fatal. Moreover, these conditions afflict people of all ages. An estimated 165,000 children have arthritis or a related joint disease, and many will carry a serious handicap into adulthood.

Arthritis and musculoskeletal pain account for the largest proportion of new pain symptoms reported to physicians. Osteoporosis, a condition in which bone mass decreases, is the leading cause of bone fractures in postmenopausal women and in the elderly. The prevalence increases with age, and the disease affects 90 percent of women over 75. Low back pain is a major national health problem, a crippling ailment of staggering dimensions. According to a recent report, this ailment is the leading cause of limitation of activity in young adults 17 to 45 years of age. More than 30 million young Americans participate in organized sports and one in two adults exercises regularly. An estimated 17 million persons sustain significant injury from sports or recreational activities each year.

Arthritis and related disorders cost the Nation an estimated $31 billion annually in medical expenditures and associated economic losses. Because a large percentage of those with arthritis and related disorders are 65 years of age and older, much of this economic burden falls on public resources such as Medicare and Medicaid.

Advances in diagnosis and management of arthritis and musculoskeletal and skin diseases over the past two decades have been substantial. Already, with funding provided by the Congress, great strides have been made under the direction of NIAMS in improving the quality of life for all Americans. The following are examples of just a few of these success stories.

Drug therapies for the inflammatory arthritides such as rheumatoid arthritis, lupus, and ankylosing spondylitis are far more effective and considerably less toxic. Total joint replacements of hip, knee, fingers, and shoulders for patients with rheumatoid or osteoarthritis are now much more reliable and can be introduced with low morbidity or mortality. Sports injuries are better treated and much treatment is through the arthroscope. Pemphigus, a formerly fatal skin disease, can now be treated effectively for long periods of time; and osteoporosis and other metabolic bone diseases can be diagnosed much earlier by use of newer imaging systems and treatment instituted in time to avoid fractures.

Clearly though, much more must be done. We stand on the threshold of discovery in a number of areas principally as a result of knowledge gained by technological advances in such areas as molecular biology, immunology, bioengineering, magnetic resonance spectrometry, photobiology, and biochemistry. Scientists in our various disciplines are embarked on such projects as a search for the infectious agent in rheumatoid arthritis; control over the immune mechanisms of lupus; definition of the role of low molecular weight mediators in cartilage destruction and restoration; improved and more durable fixation of prosthetic implants; safer and more predictable allograft transplants, prevention of skeletal bone loss by combinations of vitamin D, parahormone, and estrogens; and the use of retinoids, ultraviolet light, and newer drugs in the management of skin disorders.

Currently, 62 percent of the NIAMS' budget is spent on research grants, the highest percentage of any Institute at NIH. Since 1977, the average priority scores for successful NIAMS grant applications have reflected a steady, impressive improvement in the scientific quality of the applications received, thus enhancing the competition for the scarce budgeted dollars and driving the payline or priority score for funding to an all-time low, the lowest, in fact, of all the Institutes. The 1987 priority score cutoff for NIAMS was 147, while the mean for the other Institutes was approximately 160, with a high around 200. It is anticipated that the cutoff will drop to 140 in FY 1988 and 1989, which means that only about one quarter of the approved grants can be funded. Furthermore, if the current projected budget figures remain as proposed, each of the approved grants will have to suffer a devastating 12 to 13 percent cut in funds.

In yet another important area, funding for training grants of all sorts has been seriously reduced to the point where far fewer than 20 percent of them get funded. This greatly impacts on young people who are obviously getting discouraged with what seems to be insurmountable obstacles to becoming a productive career scientist in this important field.

It is the recommendation of the NAAB that sufficient monies be added to the budget to restore the payline to 190, which would allow funding of 50 percent of the approved research grants. In addition, we would hope that the Congress would vote for sufficient funds to allow NIAMS to fund several more research centers in the fields of arthritis, musculoskeletal, and skin diseases, pay centers at their full current recommended levels, increase the budget for intramural research, and vastly increase the current budget for training grants so that more young people with new ideas could enter and participate in this important research.

The results of research must travel from the laboratory to the patient. Support for public and patient education programs is equally important, especially in these areas of chronic, often lifelong diseases. Patients need to be informed accurately about their condition, the medications they take, and the physical and emotional and social assistance they can access as they struggle to cope with their situation and lead as normal a life as possible. The Board strongly supports the public information and professional and patient education programs of NIAMS, particularly those of National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse, that provide accurate, scientifically based information and education materials to physicians and other health professionals, patients, and the general public.

By way of summary, the problem of arthritis and musculoskeletal and skin diseases affects millions of Americans over long periods of time; most are chronic diseases that are at best manageable, not curable--yet. With the concern and support of Congress over the past 10 years, progress has been made in the basic sciences related to the wide spectrum of these disorders. Moreover, in many cases, these research results have been implemented and applied to patients, bringing relief and hope to millions of Americans.

To do all of this, we respectfully request that the Congress increase the allotment to the NIAMS to the level of approximately $253,000,000 for the next fiscal year. The progress we would achieve with our increased ability to fund grants, train scientists, and maintain our centers would be very gratifying to you and it would enormously benefit your constituencies . . . the American public.

Thank you for the privilege of appearing before your subcommittee. I will be pleased to respond to any questions you may have.

Senator CHILES. We thank you very much, and especially for the testimony you give us about your individual case. That speaks very eloquently for the work that we should and have been doing on this subcommittee and what we will continue to do, and what the Congress has done.

We thank you very much.

Ms. DRUMMY. Thank you.

Senator CHILES. I am delighted to hear of your progress.

Ms. DRUMMY. Thank you.

SUBCOMMITTEE RECESS

Senator CHILES. The subcommittee will now stand in recess until 9:30, June 7, when we will resume our hearing of public witnesses.

[Whereupon, at 12:06 p.m., Thursday, May 26, the subcommittee was recessed, to reconvene at 9:30 a.m., Tuesday, June 7.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1989

TUESDAY, JUNE 7, 1988

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:30 a.m., in room SD–192, Dirksen Senate Office Building, Hon. Tom Harkin presiding.

Present: Senator Harkin.

Also present: Senator Melcher.

NONDEPARTMENTAL WITNESSES

Senator MELCHER [presiding]. The subcommittee will come to order. This morning the subcommittee will continue with the seventh of 9 days of hearings with public witnesses, with testimony focusing on the programs funded by the Subcommittee on Labor, Health and Human Services, Education and the 14 related agencies.

During these several sessions, the subcommittee will hear testimony from approximately 225 witnesses, the highest number yet to be heard by the subcommittee in a single year. Because of the large number of witnesses, we must request that each witness keep their oral testimony brief. You should be assured that your full statement will be included in the printed record.

In order to help us stay on schedule, we are going to use a green-red light system. When the red light goes on, your 3 minutes have expired. We will need to ask each of you to conclude your remarks when the red light goes on, so that each witness will have a fair and equal opportunity to be heard.

Before we call the first witness, let me explain a little bit why I am here. I asked to testify to the subcommittee on the point dealing with chimpanzees and medical research.

I think there is some uncertainty involved on whether or not international agreements that would ban the capture of chimpanzees in countries abroad would somehow be watered down or avoided in some way. And because of that concern I have a concern, because I do not want that to happen.

In order to avoid that I would suggest to the subcommittee that appropriate language be inserted in this year's bill to make sure that we are not involved through NIH in any attempt to avoid or to water down the prohibition of taking chimpanzees from their native habitat for purposes of research contrary to international agreements that are now in place.

Having stated that, I have therefore given my testimony before this subcommittee and will proceed with the rest of the witnesses.

STATEMENT OF DR. NORVAL W. KING, JR., NEW ENGLAND REGIONAL PRIMATE RESEARCH CENTER, HARVARD MEDICAL SCHOOL

Senator MELCHER. Our first witness this morning is Dr. Norval W. King, Jr., with the New England Regional Primate Research Center at Harvard Medical School. Please proceed, Dr. King.

Dr. KING. Good morning. Chairman Melcher, I am Dr. Norval King.

I am an associate professor of comparative pathology and associate director of collaborative research at the New England Regional Primate Research Center at the Harvard Medical School. I will be presenting this testimony on behalf of Dr. Ronald Hunt, who is the director of the New England Regional Primate Research Center.

I am here today representing all seven of the NIH-sponsored primate research centers, each located at a distinguished university in the States of Louisiana, Wisconsin, Georgia, Washington, Oregon, California, and Massachusetts.

I thank the committee for the opportunity to appear before you. As you know, Dr. Hunt has met with this committee on a number of occasions, and he appreciates the consideration and the positive responses that you have shown to the primate center program over the years.

Today I wish to make the committee aware of a number of events and circumstances that tax the very ability of the primate research centers to adequately carry out their missions.

The regional primate research centers were established by the U.S. Congress in 1960, after 3 years of intensive study to determine the Nation's needs regarding nonhuman primates in biomedical and behavioral research.

Congress made funds available to universities from 1960 through 1962 on a competitive basis for construction of the centers, and by 1965 all seven were complete and the research programs were in operation.

Some 23 years later, the centers continue to operate by competitive core grants awarded by the Division of Research Resources of the NIH, and individual awards to investigators from the categorical institutes.

Because of their unique characteristics, nonhuman primates are crucial for many medical research studies with animals, studies that must precede human research and the application of that research.

Center breeding programs and research on the biology of primates have been critical to ensuring the primates remain available to scientists throughout our Nation. Now that so many species have become endangered, or threatened with extinction or cannot be imported, owing to exportation bans imposed by their native countries, the importance of the role of the primate centers cannot be overemphasized.

The need to maintain large breeding groups not planned for in the original construction of these facilities has, however, taxed the center resources.

The centers also serve as a scientific resource for the biomedical community at large. Scientists from other institutions throughout the United States depend more and more on primate center resources and services.

Collectively, the seven centers assist approximately 1,300 investigators who use nonhuman primates as the most appropriate models for investigations of the important human health problems.

Many university departments and research institutions have drastically reduced and in some areas eliminated the use of primates because of their requirements for higher standards, and consequently higher costs for animal housing and the inherent difficulties in managing primate colonies and the need for specially trained personnel.

It is not surprising that these institutions and their researchers are increasingly turning to the regional primate research centers to carry out such work. I see the red light is on. I am going to go to the very bottom of the statement.

Dr. Hunt suggests that the committee examine two measures very carefully. One, to view the appropriations for the primate research centers program, and to make every effort to approach the NIH-approved funding level of $34 million.

Two, to provide the congressional authorization for construction and funding, without a requirement for matching funds, thus allowing greater flexibilities for the centers to construct housing and breeding facilities, research laboratories, and support facilities.

PREPARED STATEMENT

The matching funds requirement is a constraint currently that is attributed to the lack of expansion and the needed capital improvement to the center. Thank you very much, Mr. Chairman.

[The statement follows:]

STATEMENT OF DR. NORVAL W. KING, JR.

I am Dr. Norval W. King, Jr., Associate Professor of Comparative Pathology and Associate Director of Collaborative Research at the New England Regional Primate Research Center at the Harvard Medical School presenting this testimony on behalf of Dr. Ronald D. Hunt, Director of the New England Regional Primate Research Center. I am here today representing all seven of the NIH-sponsored Primate Research Centers, each located at a distinguished University in Louisianna, Wisconsin, Georgia, Washington, California and Massachusetts.

I thank the Committee for the opportunity to appear before you. As you know, I have met with this Committee on a number of occasions and I appreciate the consideration and the positive responses that you have shown to the Primate Center Program over the years. Today I wish to make the Committee aware of a number of events and circumstances that tax the very ability of the Primate Research Centers from adequately carrying out their missions.

The Regional Primate Research Centers were established by the United States Congress in 1960, after three years of intensive study to determine the Nation's needs regarding nonhuman primates in biomedical and behavioral research. Congress made funds available to universities from 1960 through 1962 on a competitive basis for construction of the Centers and by 1965 all seven were complete and the research programs were in operation. Twenty-three years later, the Centers continue to operate by competitive core grants awarded by the Division of Research Resources of N.I.H. and individual awards to investigators from the categorical institutes.

Because of their unique characteristics, nonhuman primates are crucial for many medical research studies with animals; studies that must precede human research and application. Center breeding programs and research on the biology of primates have been critical to ensuring that primates remain available to scientists throughout our Nation. Now that so many species have become endangered or threatened with extinction or cannot be imported owing to exportation bans imposed by their native countries, the importance of the role of primate centers cannot be overemphasized. The need to maintain large breeding groups, not planned for in initial construction of facilities has, however, taxed Center resources.

The Centers also serve as scientific resources for the biomedical community at large. Scientists from other institutions throughout the United States depend more and more on Primate Center resources and services. Collectively, the seven Centers assist approximately 1,300 investigators who use nonhuman primates as the most appropriate models for investigations on important human health problems. Many university departments and research institutions have drastically reduced and, in some areas, eliminated the use of primates because of requirements for higher standards and consequently higher costs for animal housing and the inherent difficulties in managing primate colonies and need for specially-trained personnel. It is not surprising that these institutions and their researchers are increasingly turning to the Regional Primate Research Centers as places to carry out their work. Additionally, the biotechnology revolution is creating a vast new group of bioengineered products that will be used to treat everything from heart disease to AIDS that can only be studied and tested in nonhuman primates. The full impact on Primate Centers is yet to be realized. The Primate Centers are having an increasingly difficult time in accommodating this valid and needed research. This trend has also taxed Center resources.

Research using primates has and is continuing to contribute to many important diseases of mankind. These include heart disease, which will claim over 500,000 lives this year in the United States; hypertension or high blood pressure, which affects one-third of our adult population; malaria, which at any given moment affects 100 million persons; leprosy, a disease affecting 15 million people and on the increase; Parkinson's disease, an illness which afflicts approximately a million individuals in this country; ulcerative colitis, which affects 300,000 to 500,000 Americans and places them at 15 to 30 times the normal risk of colon cancer; and, drug addiction which has been named a National Crisis. These are but a few of the maladies being studied at Primate Centers. Most recently, another National Crisis has been addressed by the Primate Center Program - AIDS. I needn't elaborate on this National and International epidemic caused by a virus estimated to infect 1.5 million Americans and up to 10 million people worldwide. The Primate Centers' response to this catastrophe has been impressive. An excellent animal model has been developed and is presently being pursued to develop a vaccine and to better understand how the virus induces disease. The Primate Center effort, however, has further taxed Center resources at the expense of other programs.

Primate Centers face yet another challenge - meeting the spirit of the amendments to the Animal Welfare Act recently passed by the Congress. This law requires that the Primate Centers and other institutions provide for the psychological well-being of nonhuman primates. Although this law was well-intentioned, it is impossible to define. The first draft of the regulations to enforce the law as proposed by the United States Department of Agriculture would drastically disrupt biomedical research dependent upon nonhuman primates. At the very least, the proposed regulations would cut the research effort in half and simultaneously cost millions of unbudgeted dollars. This will surely tax the Centers.

The operating budget for the Primate Centers has not grown in real dollars for several years. Congress has made available periodic funding for modernization and rennovations of facilities and supplemental funding has been provided for research on AIDS, but the base budget which provides for the infrastructure of the Center - the salaries of key personnel, heat and the like - has not appreciably changed. The current base funding of the seven centers is about 23 million dollars (not including improvement funds and AIDS funds). The recommended budget, established by peer review of the program and approved by the National Institutes of Health is about 34 million, including all indirect costs. The difference of 11 million dollars is significant. Although some of this difference has been made up through AIDS funding and improvement funding, these latter programs do not impact on the Centers total program. As I stated, the AIDS research effort has been at the expense of other programs. Also, these supplemental funds cannot be planned on, nor do they lend stability to the program for planning or execution.

These five issues:

1. The need to ensure the continued availability of nonhuman primates through breeding programs in facilities not intended for this purpose;
2. The increased demand on the Centers by other institutions;
3. The diversion of resources from valid and needed research to research programs on AIDS;

4. The new law requiring for the psychological well-being of nonhuman primates;

   and

5. An essentially static operating budget

place the Primate Centers Program, and the much needed research dependent upon primates in our Nation, in jeopardy. The facilities and resources are inadequate to carry out our legitimate growing mission.

I ask the Committee to examine two measures very carefully:

ONE: Review the appropriation for the Primate Centers Program and make every effort to approach the N.I.H. approved funding level of 34 million dollars;

TWO: Provide congressional authorization for construction and funding without a requirement for matching funds, thus allowing greater flexibility for the Centers to construct housing and breeding facilities, research laboratories and support facilities. The matching funds requirement is a constraint that has contributed to the lack of expansion and needed capital improvements to Centers that have not kept pace with the research requirements. The specific budget and space requirements for the Center Program has been provided to the N.I.H. and in previous testimony to the House of Representatives Subcommittee on Health and Education by Dr. Frederick King, Director of the Yerkes Regional Primate Research Center in Atlanta, Georgia.

The directors of the seven Regional Primate Research Centers very much hope that members of the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations will take our request under serious consideration in the interest of solving many of our nation's health problems.

Senator MELCHER. Let us see. First of all, Dr. King, you are reading Dr. Hunt's testimony?

Dr. KING. That is correct.

Senator MELCHER. Are you and Dr. Hunt satisfied that the NIH breeding program will satisfy the needs for primates without importing any additional primates?

Dr. KING. I think most of the centers currently tend to be self-sufficient, although with the increased emphasis I think on AIDS research the demand has certainly increased within the last couple of years.

There is going to be a sort of shortfall there, I think, until some of the centers are able to upgrade or bolster their breeding program.

Senator MELCHER. You say that the first draft of regulations to enforce the 1985 amendments to the Animal Welfare Act, that is psychological well-being of primates, have you seen a first draft? I have not been able to get a hold of one.

Dr. KING. Dr. Hunt has seen a portion of the first draft, I think.

Senator MELCHER. A portion of the first draft.

Dr. KING. That is my understanding. I personally have not seen it.

Senator MELCHER. And Dr. Hunt seems to think that it is impossible to define the psychological well-being of primates. Do you share that view?

Dr. KING. I am not quite sure that is his view. We at the New England Primate Center are in the process actually of putting together a white paper on what we think psychological well-being of nonhuman primates should be. Not that that should be the absolute model, but it is going to be a starting point, we hope.

Senator MELCHER. Well, exercise is something interesting happening, and space is all involved, is it not?

Dr. KING. Yes.

Senator MELCHER. And that is easy to define those three things, is it not?

Dr. KING. Space is the critical issue in terms of exercise, as I understand what the new requirement is going to be.

And so without additional space, it is going to be either a matter of reducing the numbers of primates that are currently on board in order to provide that additional space which the regulations presumably are going to require, or expanding space that we currently do not have.

Senator MELCHER. And you are recommending that there be cost-sharing for any additional space. Is that right?

Dr. KING. Well, his testimony indicates that it should not be cost-sharing.

Senator MELCHER. What should it be?

Dr. KING. Pardon?

Senator MELCHER. What should it be?

Dr. KING. He is asking that the NIH, or the Congress give authorization to the NIH for construction funds that do not require matching funds.

Senator MELCHER. Do not require matching funds.

Dr. KING. That is correct.

Senator **Melcher**. All right. Glad to hear that point clarified. I might have read Dr. Hunt's testimony too rapidly.

Dr. **King**. I think the last page indicates——

Senator **Melcher**. Would that be just for the primate centers?

Dr. **King**. I am only testifying on behalf of the primate centers. I think other agencies would like that authority as well.

Senator **Melcher**. Did you not mention there are seven primate centers?

Dr. **King**. That is correct.

Senator **Melcher**. Two of them in California?

Dr. **King**. One in California.

Senator **Melcher**. One in California. Which one?

Dr. **King**. One at Davis.

Senator **Melcher**. One at Davis.

Dr. **King**. There is one in Oregon, Washington, California, Wisconsin, Louisiana, Atlanta, GA, and Massachusetts.

Oregon, by the way, is left off of the list inadvertently.

Senator **Melcher**. I read through that. I only saw six. I thought, well, maybe Oregon, maybe there are two in California. Thank you very much.

STATEMENT OF DR. KIRK N. GELATT, DEAN, COLLEGE OF VETERINARY MEDICINE, UNIVERSITY OF FLORIDA

Senator **Melcher**. The next witness is Dr. Kirk Gelatt. All right, dean, we are glad to have you here, glad to have you representing the American Veterinary Medical Association, and your testimony.

Dr. **Gelatt**. Thank you. Mr. Chairman and members of the subcommittee, I thank you for the opportunity to present the American Veterinary Medical Association [AVMA] and the Association of American Veterinary Medical Colleges [AAVMC] fiscal year 1989 budget recommendations for health and human services and education.

The AVMA has a membership of about 46,000 U.S. veterinarians, and the AAVMC represents the 27 American veterinary colleges as well as several veterinary science departments with about 3,000 faculty.

Both the veterinarians and veterinary colleges are concerned about funding in three areas. These include NIH, Food and Drug Administration, and the Health Resources and Services Administration. We are also concerned about the continuation of the Guaranteed Student Loan Program.

As we have already filed our written statements with you, I would like to highlight just a few of our concerns. The Division of Research Resources in NIH provides for the continued responsible use of laboratory animals.

We recommend the fiscal year 1989 budget for laboratory animal sciences and primate research be increased by $190,000 to a total of $52,920,000 to continue these programs as well as to upgrade animal facilities.

We join 170 other organizations represented by the ad hoc group of medical research to increase NIH funding by about 14 percent for fiscal year 1989 to maintain the same level of research effort as in fiscal year 1988.

The Center of Veterinary Medicine within FDA is considered by the Agricultural Committee. However, this important center for veterinary medicine is responsible for the control and the regulation of all nonbiological drugs used in animals.

There is a pressing need for more personnel and a new research building. There has been some erosion over the last few years of personnel and operating budget.

Relative to health professions education in the Health Resources and Services Administration, we support categorical grants for the health profession training to be funded at levels set in the pending legislation that would reauthorize title VII.

And last, we are concerned that the Department of Education has chosen to deny 2- or 3-year deferrals of guaranteed student loan paybacks to veterinary residents. These are young veterinarians that are in clinical training who initiated their loans prior to July 1, 1987.

PREPARED STATEMENT

We need these clinical scientists for future faculty positions as well as some of them represent the leaders of our profession in the future. Generally residency stipends are about $14,000 to $15,000 a year.

This concludes my remarks, and I thank you on behalf of the AVMA and the AAVMC.

[The statement follows:]

STATEMENT OF DR. KIRK N. GELATT

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to present the American Veterinary Medical Association (AVMA) and the Association of American Veterinary Medical Colleges (AAVMC) FY 1989 budget recommendations for Health and Human Services and Education.

The AVMA is the national organization which represents a membership of over 46,000 U.S. veterinarians and the AAVMC represents the 27 U.S. colleges of veterinary medicine. The veterinary colleges and many of the Departments of Veterinary Science play an important part in basic medical research and applied research which contributes directly to human health. Veterinarians protect and promote human health and welfare through control and prevention of zoonotic diseases and protection of the food supply. They are also responsible for the health and welfare of animals used in biomedical research.

Veterinarians and Veterinary Colleges are especially concerned with three funding areas within the Public Health Service. These are the National Institutes of Health, the Food and Drug Administration, and the Health Resources and Services Administration. We will also comment on one aspect of the Guaranteed Student Loan program in the Department of Education.

NATIONAL INSTITUTES OF HEALTH

Division of Research Resources

The continued responsible use of animals is critical to both basic and applied biomedical research and to the development of drugs and therapies for both human and animal disease. The Division of Research Resources is the principle unit which is responsible for the use of animals in NIH research programs. It carries out 6 primary functions which are:

1. Research related to important diseases of research animals,
2. Maintains special types of animal colonies,
3. Conducts studies directed at finding new and improved animal models for human diseases,
4. Manages the Animal Facilities Improvement Grant Program to help biomedical research institutions comply with the Animal Welfare Act,
5. Operates laboratories for diagnosis and control of laboratory animal diseases, and
6. Trains graduate veterinarians as specialists in laboratory animal medicine to provide professional care for laboratory animals and manage animal resources at biomedical institutions.

We recommend that the FY 1989 budget for Laboratory Animal Sciences and Primate Research be increased to $52,920,000 ($190,000 above the FY 1988 outlay). This will be necessary to maintain and upgrade animal facilities, particularly in light of changes in Federal regulations and guidelines for the use and care of animals in the laboratory.

National Institutes of Health Research Programs

We join the more than 170 other organizations represented by the Ad Hoc Group for Medical Research Funding in requesting that NIH funding increase by over 14 percent in FY 1989 in order to maintain the same level of effort as FY 1988. This would permit 41 percent of all approved research project applications to be approved and it would fund approximately 7,400 new and competing renewal research project grants in FY 1989.

FOOD AND DRUG ADMINISTRATION

Center for Veterinary Medicine.

While the budget for CVM is considered with agricultural appropriations we wish to call this committees attention to the importance of the Center and urge attention to its needs. The Center for Veterinary Medicine (CVM) is responsible for control and regulation of all non-biological drugs used on animals. Over the past five years they have had a net loss of 7 percent in total personnel and a workload increase of 3 percent each year. There is a pressing need for at least $4 million for personnel and a critical need for a new research building. We hope that you will consider those needs in reviewing the FDA budget.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Health Professions Education

We are strongly opposed to the Administration's recommendation to terminate categorical grants for health professions training. Veterinary students are caught between the rapidly increasing cost of education and the relative decrease in financial aid. The number of graduates with a debt load of over $20,000 has more than doubled in the last four years and each year sees a greater and greater unmet financial need in our veterinary colleges. This is a special problem for economically disadvantaged students and we believe it is an important reason for our slow progress in expanding enrollment of minority students. Starting salaries for veterinarians remain low with the average debt load at graduation being equivalent to total first year salary.

We join the Federated Associated Schools of the Health Professions in urging that the categorical grants for health professions training be funded at the levels set in the pending legislation which would reauthorize Title VII. These levels are:

1. $325 million for the Health Education Assistance Loan program,
2. $15 million in new funds for the Health Professions Student Loan program,
3. $25 million for Exceptional Financial Need Scholarships, and
4. $32 million for the Health Careers Opportunity program

DEPARTMENT OF EDUCATION

Guaranteed Student Loan

We are very concerned that the Department of Education has chosen to interpret language in the "Higher Education Technical Amendments Act of 1987" as denying a two year deferral of GSL payback to residents who initiated their loans prior to July 1, 1987. Senator Pell has written that "The current interpretation of this provision by the Department of Education is a clear violation of Congressional intent." While this is not a primary problem for your committee we want to express our concern since it does relate to the overall need for financial aid and it does discourage excellent students from entering teaching and research programs in clinical medicine. Should Senator Pell find a legislative vehicle to correct this problem we would solicit your support.

CONCLUSION

This concludes our remarks. On behalf of the AVMA and AAVMC I want to express our gratitude for the opportunity to present our position.

Senator MELCHER. There are a couple things that disturb me, Dean. Over the past 5 years they have had a net loss of 7 percent in total personnel, and that is with the Center for Veterinary Medicine, and a workload increase of 3 percent each year.

So if you compound 3 percent you come up with about 15 percent increase in workload over the past 5 years. And it is a 7-percent drop in personnel. Why is that? Not enough money appropriated?

Dr. GELATT. I would say it is not enough money and priority.

Senator MELCHER. All right. Well, $14,000 is what a stipend is for residents. Is that adequate?

Dr. GELATT. It is at least competitive. The rate that most schools offer residents is between $14,000 and $17,000 a year.

These again would be veterinarians that have a year internship or a year training, and they are in a clinical program, not a degree program, for master's or Ph.D., a graduate student. But they are in clinical training.

Senator MELCHER. And that is adequate?

Dr. GELATT. That is adequate, yes. The problem is that we have not been able to defer their loan paybacks during this clinical training, simply because they are not graduate students.

Senator MELCHER. I see. Well, all right, thank you very much, dean, for some very good testimony. It gets right to the point.

STATEMENTS OF:

RAYMOND COTTON, UNIVERSITY OF FLORIDA COLLEGE OF MEDICINE

DR. NOEL K. MACLAREN, UNIVERSITY OF FLORIDA COLLEGE OF MEDICINE

Senator MELCHER. Our next witness is Raymond Cotton and Dr. Noel Maclaren, University of Florida School of Medicine.

Mr. COTTON. Good morning, Mr. Chairman. My name is Raymond Cotton, and with me today is Dr. Noel Maclaren, professor of pathology and pediatrics at the University of Florida College of Medicine.

I am a substitute witness for Mrs. Leatrice Ducat. Mrs. Ducat is the president of the National Disease Research Interchange [NDRI], a nonprofit tax-exempt organization whose sole purpose is to work in conjunction with the NIH and others toward assuring that researchers throughout the Nation have access to human tissues and organs that are vital in achieving breakthroughs that will lead to the prevention, treatment, and cure of many diseases.

Unfortunately, Mrs. Ducat's mother is in the hospital and she had to remain in Philadelphia, and asked me to appear before you today.

I would like to express my personal appreciation and Mrs. Ducat's and Dr. Maclaren's for the kind invitation from the chairman and the members of this committee for their support in the past, and for their allowing us to make this presentation.

The National Disease Research Interchange was established in 1980 and pioneered the world's first retrieval, preservation, and distribution mechanism designed to assure researchers access to human tissues and organs, alternative resources that are proving to be so vital in increasing our understanding of so many diseases. Dr. Maclaren in his statement will specify some of those.

The diseases that NDRI is working with number over 80, and they have supplied tissue to over 130 researchers throughout the United States.

NDRI, the major difference which sets NDRI apart from other organizations involved in the procurement of human tissue is that it provides the whole process, retrieval, processing, and delivery, as a uniquely individualized service to each participating clinical investigator or research investigator.

NDRI is not a tissue bank, and as its name implies NDRI serves as an interchange between human tissue resources, for example hospitals, organ recovery programs, eye banks, and the investigator who requires a reliable steady supply prepared precisely for his or her research needs.

At this point, Mr. Chairman, I would like to turn to my colleague so that he can share with you some scientific evidence.

Dr. MACLAREN. Thank you. Mr. Chairman, members of the committee, I am professor and chairman of the Department of Pathology and Laboratory Medicine at the University of Florida College of Medicine. I have been in the area of diabetes research for more than 15 years. I am also a member of the steering committee of the National Disease Research Interchange.

NDRI is the main resource for the procurement of human tissues that are vital to the diabetes research effort. NDRI is a prototype system that was established in 1980 by Mrs. Lee Ducat that successfully retrieves, preserves, and transports human tissues and organs that would otherwise be discarded.

NDRI networks contribute over 130 different types of human body tissue to be used in research of some 80 diseases, including cancer, diabetes mellitus, hyaline membrane disease, and cystic fibrosis, amongst others.

More specifically in my field, the onset of insulin-dependent diabetes is preceded by inflammation of the pancreatic islets that selectively destroy the insulin-secreting beta cells in the pancreas. The process often takes years.

Human pancreases are needed to detect fetus cell auto antibodies in the blood that are markers for the disease. And NDRI is the only organized supplier of such tissue. Detection of such auto antibodies can be used to predict onset of diabetes months and years before those who are destined to develop the disease actually do so.

And this is again possible only because the NDRI can procure the required viable human pancreases from kidney donors. The hope is that through early detection the disease may ultimately become one that is preventable.

For the millions of Americans today who require daily injections of insulin, one of the brightest research hopes lies in the transplantation of viable beta cells.

PREPARED STATEMENT

I will emphasize that my field of expertise only represents one of those areas of research that cannot proceed without the NDRI, and I urge your committee to provide adequate funding for the organization, that is, $5 million of the fiscal year 1989. Thank you.

[The statements follow:]

STATEMENT OF LEE DUCAT, PRESIDENT, NATIONAL DISEASE RESEARCH INTERCHANGE

I am Lee Ducat, Founder and President of the National Disease Research Interchange (NDRI), a nonprofit, tax-exempt organization, whose sole purpose is to work in conjuncture with the National Institutes of Health (NIH) and others toward ensuring that researchers throughout the Nation have access to the human tissues and organs that are vital in achieving breakthroughs that will lead to the prevention, treatment, and cure of so many diseases. I also served on the Diabetes Commission, two National Diabetes Advisory Boards and on the Task Force on Organ Transplantation. Testifying with me today is Dr. Noel K. Maclaren, Professor of Pathology and Pediatrics at the University of Florida College of Medicine.

I would like to begin by thanking you for affording me this opportunity to testify on behalf of NDRI. NDRI appreciates being able to present, as well, our recommendations to this Commission on Fiscal Year 1989 appropriations for NIH and, in particular, the Division of Research Resources (DRR).

I would also want to express my personal appreciation to Chairman Chiles and the members of the Committee for their past support not only for NDRI, but especially for their staunch commitment to NIH. There are truly millions of Americans who owe their lives to the important work being done by the NIH.

It is very easy, indeed, in a time of fiscal constraints to lose sight of the fact that the relatively small investment in NIH has no doubt saved the Nation billions in health care costs, lost wages, and productivity.

I dare say that there are thousands of people, probably millions, who unfortunately do not truly appreciate that their good health is due to the work done by NIH over the past one hundred and one years. I urge you to remain firm in your support for NIH.

NDRI was established in 1980. And, I am proud to say, pioneered the world's first retrieval, preservation, and distribution mechanism designed to assure researchers access to human tissues and organs -- alternative resources -- that are proving to be so vital in increasing our understanding about so many diseases. In seven short years, there has been an explosion in the demand for and recognition about the utility of conducting research using these alternative resources, due in large part to advances in molecular biology, genetics, and other advances in biomedical science. The demand for access to alternative resources is increasing by the day, if not by the hour!

As we all know, excellence in science today is dependent upon investigators having access to sophisticated instrumentation, well-equipped laboratories, information about new technologies, clinical research centers for the application of laboratory advances to human health care, large capacity computers, and the availability of biological materials and models critically needed for the study of human disease. The Division of Research Resources, through its six extramural programs is the primary component within NIH which provides support for these types of research resources.

In its 1985 report entitled, "Models for Biomedical Research, A New Prespective," the Committee on Models for Biomedical Research commented that for many scientific problems the best model for research is the species closest to the human in terms of its taxonomy and physiology. Clearly, this conclusion underscores what scientific experts tell us: human tissue is vital in its use as an alternative resource to animal systems and organs.

Not only is human tissue more easily applicable to the human condition, but for most of the major diseases very few, if any, animal models exist. Thus, human models are sorely needed to explore diseases like cystic fibrosis, lupus, diabetes, and AIDS. The cures for many of these tragic diseases may very well depend on the human model and on the various disease tissues which can be retrieved for research. Research utilizing animals has and will continue to be essential to our making progress in the war against diseases. However, the point needs to be emphasized: funding to support alternative resources which do not rely on the use of animals is a pressing need. It will advance scientific understanding. Not only will it corroborate research findings using animals, but it will allow us to study diseases for which there are no animal models.

I would like to take a moment to briefly describe what led to the creation of NDRI and its evolution. In 1971, I founded the Juvenile Diabetes Foundation (JDF). My son had developed diabetes and as I learned about the disease I realized the pressing need to gain support to accomplish more effective modes of treatment, prevention and, ultimately, a cure. This led to the creation in 1980 of the National Diabetes Research Interchange. Initially under the sponsorship of JDF, NDRI was designed to accelerate diabetes research, possibly by decades, by providing access to human models for laboratories and researchers, which had heretofore relied on animals for biomedical research.

This program was designed with the help of top scientists throughout the Nation, including representation from NIH.

It quickly became apparent, however, that researchers across the Nation conducting biomedical research searching for the cure and prevention of many diseases were unable to obtain the human tissues and organs necessary to carry out their vital work.

The challenge to obtain this precious resource was a costly and difficult one. With financial support and expert guidance from private foundations and the federal government, particularly through the NIH, NDRI has helped meet that challenge and has created and designed a prototype system to retrieve human tissues and organs which would otherwise have been trashed, incinerated, discarded or wasted. To date, NDRI has supplied more than 35,000 tissues and organs donated for research to over 350 scientists throughout the United States and Canada.

NDRI networks contribute over 130 different types of human body tissue used in the research of some 80 diseases, including Cancer, Diabetes Mellitus, Hyaline Membrane Disease, and Cystric Fibrosis. For over half a decade, hundreds of people have cooperated to establish a scientifically viable, highly efficient system to identify, obtain and deliver human tissues and organs to investigators at the world's most renowned universities, hospitals and medical research centers. The existence of a national network of sources provides both normal (control) and diseased tissue reliably prepared according to individualized scientific protocols from tissues donated at autopsies, surgical procedures, and organs which cannot be used for transplants.

Two leading scientists had the following comments about the important role of NDRI in helping to assist scientific research:

> The scientific community owes a tremendous debt of gratitude...for their (NDRI's) remarkable efforts in establishing this organization as a vital resource for not only basic investigations in human diseases but also for making it possible to initiate the use of human islets for the clinical trials on human islet transplantation in diabetes.
>
> Paul E. Lacy, M.D., Ph.D
> Robert L. Kroc, Professor of Pathology
> Washington University School of Medicine
> Chairman Emeritus, NDRI Steering Committee

> The potential of using human tissues in the investigation of Diabetes, Cancer, Atherosclerosis and other diseases has been realized, and the NDRI is now recognized as a research resource with the broadest applicability and with overwhelming importance. Scientists everywhere now know that they can rely on the NDRI to meet their ever expanding needs in studying human disease with this most precious of research commodities.
>
> Howard S. Tager, Ph.D.
> Chairman, Department of Biochemistry and Molecular Biology
> University of Chicago School of Medicine
> Chairman, NDRI Steering Committee, 1984-1986

Since its creation, NDRI has focused on broadening the scope of the disease categories it serves. To reflect this broader purpose, NDRI in 1986 became the National Disease Research Interchange. Advisors from NIH participated in the design of NDRI and its system since inception of the NDRI concept, to its emergence as a resource today to serve the needs of all researchers.

NDRI is honored to have been funded by NIH through the Division of Research Resources, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Heart, Lung and Blood Institute, and the National Cancer Institute.

The major difference which sets the NDRI apart from other organizations involved in the procurement of human tissue is that it provides the whole process, retrieval, processing and delivery, as a uniquely individualized service to each participating investigator. NDRI is not a tissue bank. And as its name implies, NDRI serves as an "interchange" between human tissue sources, i.e., hospitals, organ recovery programs, eye banks and the investigator who requires a reliable, steady supply prepared precisely for his or her research needs. Most tissues procured by NDRI are in and out of the system within hours. Frozen tissue is shipped on a regular monthly schedule at the convenience of the recipient. The flexibility offered in the design of each individual protocol makes the NDRI service far more valuable and needed among those participating investigators who otherwise might be restricted to accepting specimens prepared according to a limited selection of generalized protocols or to spending hours waiting to retrieve the required fresh specimens themselves. Some have no access to fresh, viable specimens at all.

Recent major initiatives by NDRI include:

- Islet Cell Isolation & Transplant: NDRI's support of diabetes research has long been documented. With the establishment of an NDRI satellite at the Washington University School of Medicine, under the direction of Dr. Paul E. Lacy in 1983, NDRI made the commitment to assist in the development and continuation of human islet cell research with the goal of finding new methods to treat and cure Diabetes Mellitus. Since that time, NDRI efforts in the procurement of both adult and fetal pancreas have been increasingly sophisticated. The retrieval is significant when viewed from the historic point of view that human pancreas was retrieved rarely and that researchers doing pancreas research had almost never seen a human pancreas. NDRI satisfied its charge to initiate and nurture the networks that would retrieve human pancreas for research in a regular and continual way. Current experiments with islet cell technology which project the successful implant of functioning cells to replace defective ones, holds tremendous implications for the future treatment of not only diabetes mellitus, but a host of other diseases.

- Retrieving Cancer Tissue:
  In January 1987, a three year contract of major importance was awarded by the National Cancer Institute to NDRI in collaboration with the University of Pennsylvania Medical Center in Philadelphia. NDRI and the University of Pennsylvania have been chosen as the Eastern Division Center, one of three centers in the United States to comprise a "National Cancer Institute Cooperative Human Tissue Network." The other two centers are at Ohio State University and the University of Alabama at Birmingham.

  The Cooperative Human Tissue Network was created to improve access to expertly prepared and well-documented human tumor and related normal tissue for cancer research. Investigators,

> particularly those who do not work in major medical centers, have difficulty obtaining access to human cancer tumor tissue. The Network was organized to serve these needs and to stimulate research using human cancer tissue, particularly in molecular biology and genetics.

NDRI was deeply appreciative of the language included in last year's Senate Report which stated:

> "The Committee strongly supports the development and utilization of alternative research models which do not rely on the use of animals. Among those alternatives is the National Disease Research Interchange [NDRI] whose mission is to ensure regular access to human tissues and organs for biomedical researchers throughout the country. ...The Committee expects the Division of Research Resources, through the Biological Models and Materials Resources Section [BMMRS], to give efforts such as these high priority in fiscal year 1988." ((P.132)

Indeed, the DRR is the focal point for developing the NIH plan mandated by P.L. 99-158 to develop "research methods that do not use animals..." NDRI is proud of the role it has and will continue to play in not only meeting this mandate, but in working with NIH to fight diseases.

Given the demonstrated economic soundness of biomedical research activities, increased appropriation levels for NIH, and particularly the Division of Research Resources, must be a national priority. NDRI believes that the President's budget request for the Division of Research Resources of $319,977,000 is inadequate. A .07% increase over the 1988 level is unacceptable.

NDRI believes that in order for the Division of Research Resources to be able to continue to meet its mandate and provide the leadership which is crucial to our national research effort, an appropriation level of $452.828 million is necessary for fiscal year 1989. We also request that $5 million of this appropriation figure be designated to support the work of NDRI, so that we can expand to meet the needs of NIH researchers in all disease categories. For the support of alternative resources, we recommend $15 million in funding.

It is crucial that the Committee truly appreciate that the demand by researchers for alternative resources is exploding. And funding to support the development and availability of alternative resources must be increased to a level that reflects this growing demand. In order to find cures for major diseases like AIDS, Cancer, and Diabetes researchers simply must have access to these vital alternative resources.

The aim of, the conception of, and design of NDRI at its inception, a privately funded project supported by the Pew Memorial Trust, included that the appropriate home for the National Disease Research Interchange would be the National Institutes of Health. It would be our greatest honor to continue to serve the Nation and the original aim of the designers of this prototype, very simple, yet revolutionary system which has emerged as the first new research resource in biomedical research in the last one hundred years.

NDRI further recommends that for NIH as a whole, the Committee accept the recommendation of the Ad Hoc Group for Medical Research and provide funding for $8.471 billion in FY 1989.

On behalf of NDRI, thank you for allowing us this opportunity to present our views. We would be pleased to answer any questions you may have.

Senator **Melcher**. All right. About how much are you spending from NIH through NDRI this current fiscal year?

Mr. **Cotton**. Approximately $3 million.

Senator **Melcher**. Well, the committee has supported the use of human tissue in research. I am sure their support will continue. To the extent that it can be used, it is a better source than research, for instance, on primates. Thank you very much for your testimony.

Mr. **Cotton**. Thank you very much, Mr. Chairman.

Senator **Melcher**. Leslie Fain, legislator director for the Committee for Humane Legislation. Leslie Fain is not here.

STATEMENT OF DR. C. MAX LANG, SECRETARY-TREASURER, AMERICAN COLLEGE OF LABORATORY ANIMAL MEDICINE

Senator **Melcher**. Dr. Lang, secretary-treasurer of the American College of Laboratory Animal Medicine.

Dr. **Lang**. Thank you for the opportunity to be here this morning to testify in support of the NIH budget, particularly that for the Division of Research Resources.

As we all know, the average age of Americans is increasing. This, in turn, will require increased research activities. Some of these requirements will include research on the more than 100 different kinds of cancer, new diseases such as AIDS, and more efficient forms to reduce health care costs. Animals have had and will continue to have an important role in these research activities.

The American College of Laboratory Animal Medicine is committed to the provision of humane care for these animals. You have shared our concerns in the past by passing legislation on animal welfare, and we now need your support in two key areas.

The first is training of personnel to provide optimal care of research animals. The second is laboratory diagnostic support to complement these clinical skills.

PREPARED STATEMENT

Your support of this project will enable us to; one, provide adequate numbers of trained individuals; two, further enhance the quality of humane animal care; three, reduce the number of animals required for statistically valid data; and four, contribute new information on the health care needs of both people and animals. Thank you.

[The statement follows:]

STATEMENT OF DR. C. MAX LANG

The specialty of Laboratory Animal Medicine was developed in response to a perceived need among biomedical research institutions to train veterinarians in the proper care and treatment of animals used in research. It is noteworthy that the American College of Laboratory Animal Medicine was the second specialty of veterinary medicine. Formally recognized by the American Veterinary Medical Association in 1957, it culminated the efforts of veternarians in the two previous decades to (1) recognize the importance of animals in solving both human and animal disease problems; (2) proficiency in the special training that is required for the care and use of research animals; and (3) the best research data is obtained from healthy animals that are properly cared for in a controlled environment.

The Subcommittee on Labor, Health and Human Services, Education, and Related Agencies throughout these deliberations - will hear and read repeated requests for funding research activities on cancer, heart disease, diabetes, cystic fibrosis, etc. It is important to realize, almost without exception, that these research programs are dependent on animals.

The Congress in the last two decades, has responded to public concerns about how animals are housed, cared for, and used in research. However, the forerunner of these concerns began in the biomedical research community, especially the veterinary profession. Members of the biomedical research community have actively worked with the Congress to ensure that these standards are, in fact, understood and implemented. However, it is frustrating because Congress has been hesitant to provide the resources to accomplish the intent of these legislative matters.

The proper care and use of research animals - including using the minimum required and consideration of alternative methods - requires: (1) adequate facilities that will minimize the influence of environmental variables that can complicate the interpretation of research data; (2) trained individuals who can ensure proper and humane treatment of animals, help to protect their health against diseases that could interfere with the successful completion of the research, work with investigators to ensure the use of the best animal model; and (3) adequate diagnostic laboratory capabilities to compliment the diagnostic/treatment skills of those who are committed to the care of those animals.

The proper care and use of research animals is focused, primarily, in one small part of the budget of the National Institutes of Health. I do not mean, by this statement, to belittle the efforts of our primary government agency oriented towards the implimentation of health care - for they are among the best in the world. I only want to emphasize that one small part of our health research budget is oriented towards the animals that enable us to solve those probing questions of human and animal health.

I ask you to focus on two key issues: training of personnel to adequately care for those animals; and adequate diagnostic support to aid in that care.

Training

Shortly after World War II, there were many opportunities for training in the proper care and use of laboratory animals. These included government research laboratories, the veterinary corps of the U.S. Army and U.S. Air Force, and academic institutions. However, these training opportunities have gradually diminished. This is borne out by the number of individuals meeting the requirements for certification as specialists in Laboratory Animal Medicine. For example:

> Prior to 1971, there were 141 individuals who met the requirements for certification as specialists in Laboratory Animal Medicine. Since 1970 there has only been an additional 207 individuals who are active in this specialty.
>
> Since 1970 - in five year increments - there have been: 1970-1975, 79 individuals achieving certification; 1976-80, 63 individuals, and

1981-85, 63 individuals. We have reached a dangerous - and diminished - plateau, at a time that the need is at its greatest.

The need for trained individuals is at its greatest because research with animals has become more sophisticated and even the smallest change in an animal's environment, or the effects of latent disease, can adversely affect the interpretation of research data.
A large number of specialists in this field are now reaching retirement age. For example, 56% of those individuals certified prior to 1966 have now retired. According to the current trend, it is anticipated that the number of individuals retiring will exceed the number of new individuals entering this important field.

The specialty of Laboratory Animal Medicine is committed to the quality care of research aniamls, but the limitation of trained individuals is becoming a prohibiting factor.

Thus, we urge your favorable consideration of this aspect of the NIH research budget.

Diagnostic Support

The skills of any health professional are dependent on the availability of laboratory diagnostic support. At this time, the National Institutes of Health is only able to support 15 laboratory animal research laboratories in the entire United States!

The purpose of the diagnostic laboratories are to provide for improved research animal health programs through appropriate surveillance activities and investigation of naturally occurring disease, to support studies resulting in new information on diseases of laboratory animals, to aid in the understanding of new animal models of human disease, and to develop resources for research and training. This focus on laboratory animal disease problems and research with an emphasis on diagnosis, pathogenesis, and control is unique to the Animal Resources Branch of the Division of Research Resources of the NIH.

Summary

Perhaps we, in the scientific community, have been lax in emphasing our needs. We have supported the Congress in defining the need for quality and humane care of our research animals. However, this can be accomplished only if we have adequately trained personnel to provide such care, and diagnostic laboratory support to enhance the quality of that care.

Senator MELCHER. Doctor, that is very concise and direct testimony.

I want to share with you my own view, which is supportive of your views and your organization. I think you make the right points and I think we do have to face up to the fact that we are improving the standards when we take care of laboratory animals. And as we do that it costs more money.

We do not want to cut back on the research, so I guess we have to find the dollars to make sure that the law can be adhered to and that we have better care for laboratory animals. Thank you very much, Doctor.

Dr. LANG. Thank you.

STATEMENT OF CHRISTINE STEVENS, SECRETARY, SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

Senator MELCHER. Christine Stevens, Society for Animal Protective Legislation. Christine, welcome to the subcommittee.

Ms. STEVENS. Thank you, Mr. Chairman. My testimony is fairly long so I will submit that for the record.

Senator MELCHER. It will be made part of the record, and you may summarize any way you see fit, Christine.

Ms. STEVENS. Thank you very much. First of all, I would like to express strong agreement with your own presentation at the beginning of this hearing.

And I would like to submit for the record the letter which just appeared in the international journal Nature entitled, "Chimpanzees and AIDS Research," which relates to many of the points that you made. And it concludes:

> Relaxation of the restrictions on trade in wild chimpanzees would have a devastating effect on wild populations, virtually all of which are rapidly approaching extinction.
>
> If previous practices are allowed to revive, many more chimpanzees of breeding age will be killed in Africa during crude and wasteful attempts to capture their infants for export.

The beginning of my testimony, to turn to a different point, is asking for adequate funds to provide for the psychological well-being of primates as required by the Improved Standards For Laboratory Animals Act.

That act was intended to go into effect December 23, 1986. However, because of a series of delays, nothing has come out as yet. Now, this morning, we just heard from Dr. King, and I wrote down the notes, we are putting together a white paper.

I would like to emphasize that this should have been done 2 years ago. That that is when a white paper should have been put together. And we should now have the proposed regulations at the very least. We really should have the final regulations for part 3.

I would like to quote from an NIH letter following inquiries about SEMA. Dr. Goodall wrote an excellent article in the New York Times, which I have attached to my testimony, in which he speaks of the terrible suffering of baby chimpanzees sealed off from the outside world behind the glass doors of mental isolation chambers.

Yet the NIH says it is premature to expect this institution to establish care and treatment procedures beyond that to be specified in the regulations implementing recent amendments to the Animal Welfare Act.

Why have not these regulations been made final? Who has stood in their way? NIH has been a principal source of objections and obstacles placed in the path of promulgated legislation that would improve standards for laboratory animals amendments, the Animal Welfare Act.

NIH has held up drafts of these regulations, reneged more than once, so that even now the regulations for parts 1 and 2 which were proposed in the Federal Register March 31, 1987, have not been promulgated as final. And as I mentioned, part 3 has not even come out as proposed regulations.

PREPARED STATEMENT

I see the red light has gone on. But I hope very much that this committee will take efficient action to get those regulations out and have the law go into effect, as required by Congress.

[The statement follows:]

STATEMENT OF CHRISTINE STEVENS

The Improved Standards for Laboratory Animals (ISLA) amendments to the Animal Welfare Act went into effect December 23, 1986. Although final regulations have not been promulgated, institutions using primates must necessarily recognize the important provision which mandates "an environment adequate to promote the psychological well-being of primates."

Since enactment of the law, a number of institutions have improved housing for primates by such means as joining two cages together, which formerly housed a single primate in each, and allowing two compatible primates to share the double space. The inclusion of a branch in the double cage has been instituted by some institutions and allows expanded activity by the occupants of the enclosure. Photographs show that the branch is often used by the primates. It has also been found that the majority of paired primates have been not only compatible but soon began to groom one another in a friendly manner. Serious students of primate behavior consider social grooming to be the most important bonding activity in primate groups.

The changes I have mentioned obviously do not call for major expenditures. Nevertheless, such expenditures as are required should be supplied in the pending Reauthorization Bill for the National Institutes of Health so that grantees can request the necessary funding for the specific purpose of providing for the psychological well-being of the primate subjects.

The larger and stronger primates are obviously more expensive to house. Leaving them in small, single-occupancy cages would be contrary to the intent of the law. Baboon social organization is complex, as fully documented in the recent book by Shirley Strum, Ph.D., Almost Human (Random House, New York, 1988). The book chronicles fifteen years of observing a troop of baboons. The foreword, by George B. Schaller, the world famous zoologist, points out: "These animals were most definitely aware of the consequences of their planned acts . . . Like several other recent works, Almost Human recognizes and accepts mental abilities in animals, an important reversal of a scientific trend."

Clearly, such primates require more than a barren cage to promote their psychological well-being. Some institutions may decide to use built-in partitions in rooms which formerly housed cages so that a number of animals can be kept within an enclosure that provides for the possibility of moving out of the view of the group and for a variety of activities.

Again, although the expense may not be very large, nevertheless it should be recognized as a legitimate expenditure for the specific purpose of meeting the provisions of the Improved Standards for Laboratory Animals amendments.

The housing of chimpanzees provides another example in which funds for modifying existing structures or constructing new ones should be available under the NIH Reauthorization Bill. Attached is the recommendation of the workshop on chimpanzees conducted by Dr. Jane Goodall, December 1-3, 1987. Participants in the workshop represented the following disciplines: primatology, anthropology, psychology, zoology, and virology. Those using chimpanzees for medical research and those primarily interested in the welfare of animals were included in the workshop. The recommendations were made to assist the U. S. Department of Agriculture in promulgating Part III of the regulations under ISLA.

Although the number of research institutions using chimpanzees is not large, in some cases an individual institution may house a very substantial number of chimps. Thus, the cost of providing appropriate housing may be substantial. It is important that these funds should be available under the pending bill.

To return to smaller primates, a system has been developed at one institution for regulated release of primates into areas where they can exercise, play, and use their mental capabilities on objects which cannot be kept in small cages. This system, although it does not fully meet the provision of the 1985 law, provides a useful interim measure and is deserving of financial support through NIH.

A variety of other measures which are not excessively expensive may also arise as institutions use their ingenuity to give their animals better opportunities for normal living.

The Society for Animal Protective Legislation strongly urges that the NIH Reauthorization Bill include the necessary funding to meet the requirements of the Improved Standards for Laboratory Animals Act.

I wish to request assistance from this distinguished Subcommittee with regard to three other important points:

1. Further capture of wild chimpanzees. Once present in 25 countries, chimpanzees have vanished from 4 nations, are on the verge of disappearing in 5 others, and may be exterminated in another 5 within years. No more than 5 countries today support local populations in excess of 5,000. Within this century, numbers have fallen in one region from more than 1,000,000 to less than 20,000. Scientific surveys show that about 175,000 chimpanzees may survive in Africa, dispersed over an area far greater than the entire United States.

2. Mistreatment of chimpanzees in institutions under the jurisdiction of the National Institutes of Health.

3. Delay and obstruction of regulations under the Improved Standards for Laboratory Animals amendments to the Animal Welfare Act (effective date December 23, 1986).

There is serious concern that NIH policy against capture and use of chimpanzees living in the wild is changing. I believe it would be very helpful if members of this distinguished Subcommittee could view the documentary shown April 11 by "Nature Watch," Central Independent Television in London. I would be happy to provide a copy to you. The program shows importation of wild-caught chimpanzees into Austria by the Austrian pharmaceutical house, Immuno, contrary to international treaty requirements (the Convention on

International Trade in Endangered Species of Wild Fauna and Flora). It also documents NIH's written agreement with Immuno to exchange "recombinant vaccinia viruses, materials and information" for testing on Immuno chimpanzees.

The NIH-Immuno agreement, dated July 23, 1986, came just a week before the arrival at Immuno of 20 chimpanzees from Sierra Leone. The legality of this shipment was immediately challenged by World Wildlife Fund/Austria, which, in turn, was sued by Immuno. Some 50 individuals and groups have been sued by this company on the subject of its acquisition and care of chimpanzees. Articles in The New Scientist of August 21, 1986 and in BBC Wildlife, April 1988, provide more extensive information, and I submit them for use by the Subcommittee. You will note that NIH was involved in sponsoring tests at a foreign facility using wild-caught chimpanzees, a facility which had already had other chimpanzees confiscated by Austrian authorities. This is a matter of public record, which NIH has ignored.

At a briefing held February 19, 1988 for Congress at an international conference held in Geneva March 28, 1988, NIH advocated the need for thousands of chimpanzees to be used in AIDS research. At the Geneva meeting, which was sponsored by the World Health Organization (WHO), an effort was made by NIH to have the WHO modify its standing "Policy Statement on the Use of Primates for Biomedical Purposes." The policy strongly recommends that "endangered, vulnerable or rare species be considered for use in biomedical research projects only if they are obtained from existing self-sustaining captive breeding colonies." This statement was the subject of much public criticism by Immuno in 1986-1987, which eventually prompted WHO's Director General Halfdan Mahler to issue a confirmation of the policy on April 13, 1987. But we understand that in Geneva, NIH again attempted to revise the statement so as to ease access to wild-caught chimpanzees.

Most recently a Public Health Service memo dated April 11, 1988 refers to this subject.

Chimpanzees can be and indeed are being raised in the United States. $11 million is being spent on such breeding over a four year period. Moreover in this country, chimpanzees under the jurisdiction of NIH are kept under horrible conditions. An example is SEMA, a contract laboratory for NIH, which conducts tests on chimpanzees, monkeys and other animals. An inspection report by U. S. Department of Agriculture Animal Care Specialists July 30, 1987 shows that numerous chimpanzee cages failed to meet the minimum standards required by law; nor were they cleaned regularly (for example, "Some of the cages were marked that they should have been cleaned 7-21-87 and 7-16-87"). Further, "A review of the necropsy records from July 86 to July 87 indicated 40 primates had died due to numerous causes including starvation, dehydration, intestinal problems, 'Poolesville' syndrome (retrovirus), thorny headed worm complications, pneumonia, complications to anesthetics and tranquilizers." The inspector noted a need for "more direct veterinary supervision."

Yet in a letter to Senator Robert Byrd dated December 7, 1987, NIH stated, ". . . there is no evidence that SEMA failed to comply with established laws, regulations, or policies relating to the conduct of research involving nonhuman primates, including chimpanzees."

I hope, Mr. Chairman, that you may have had the opportunity to view "20/20" on May 27 where Dr. Jane Goodall was interviewed about SEMA and the National Institutes of Health. If you or other members of the Subcommittee missed it, I would be glad to lend you a tape of the program.

Further, I would submit The New York Times article by Dr. Goodall, "A Plea for the Chimps," May 17, 1987, for additional information about confining infant chimpanzees for years in the cruel "isolettes" at SEMA. "During that time," Jane Goodall wrote, "they will become insane. A juvenile female rocked from side to side, sealed off from the outside world behind the glass doors of her metal isolation chamber. She was in semidarkness. All she could hear was the incessant roar of air rushing through vents into her prison."

Yet NIH says, "It is premature to expect this institution to establish care and treatment procedures beyond that to be specified in the Regulations implementing recent amendments to the Animal Welfare Act."

Why haven't these regulations been made final? Who has stood in their way? NIH has been a principal source of objections and obstacles placed in the path of promulgation of regulations under the Improved Standards for Laboratory Animals amendments to the Animal Welfare Act which became law December 23, 1985. NIH has held up drafts of these regulations and reneged more than once so that even now the regulations for Parts I and II, proposed March 31, 1987, have not been promulgated as final; and the regulations under Part III, which include the provision for "an environment adequate to promote the psychological well-being of primates," have not even been promulgated as proposed regulations.

We would deeply appreciate your assistance, Mr. Chairman, in bringing an end to NIH's obstructionist tactics to delay or downgrade the needed regulations.

As currently formulated and applied, federal regulations and guidelines governing the maintenance and care of captive primates used in experimental studies do not adequately address their psychological well-being. A workshop was therefore held on December 1-3, 1987, bringing together a cross-section of professionals experienced in studying both normal and abnormal chimpanzees, to consider this deficiency and to develop sound recommendations on improving the psychological well-being of chimpanzees held in laboratories and other facilities. The collective expertise of this diverse group covered many aspects of chimpanzee behavior and biology, ranging from biomedical research and veterinary care in laboratories to psychological and ethological studies in both wild and captive settings, as well as zoo administration and colony management. Conservation and animal welfare interests were also represented.

Chimpanzees are more like humans -- genetically, physiologically, anatomically, and in the structure and circuitry of the brain -- than are any other living beings. Wild chimpanzees have a long childhood of about 7 years followed by 6 or so years of adolescence during which the skills needed to succeed in adulthood must be learned through experience and from other group members. Lack of opportunity for normal development can severely impair this learning process.

Chimpanzees show many cognitive abilities once viewed as uniquely human. They are, for example, capable of reasoned thought, generalization, abstraction, symbolic representation, and self-awareness. Many of their emotions, such as joy and sadness, fear and anxiety, and even a sense of humor, are highly similar to ours. They also exhibit empathy and friendship, perform acts of true altruism, and mourn the deaths of companions. There are also many similarities in social behavior, including communicative gestures such as kissing, embracing and holding hands. Close, supportive, friendly bonds between individuals are maintained and strengthened, via social grooming and many other relaxed social activities, through spending long hours in one another's company. These relationships last for a lifespan of 40-50 years. Separation from a close companion can lead to marked distress, even among adults. Any youngster less than 5 years in age who loses a mother is likely to become clinically depressed and may even become so ill that death follows. The chimpanzee infant and the human child are alike in many ways, such as their capacity for endless romping and play, their curiosity, their ability to learn by observation and imitation, and above all in their need for reassurance and affection.

All professionals attending the December workshop agreed that, in view of the close evolutionary relationship between chimpanzees and humans, this sibling species should receive special treatment when used in the laboratory or when maintained in any other captive situation.

Despite the difficulty of adequately defining psychological needs and states for another species, it was further agreed by those attending the workshop, based on their collective expertise and the best available information, that the psychological well-being of the chimpanzee depended on provision of the following: space for vigorous activities such as running, climbing and swinging to allow adequate exercise; material for making comfortable beds as substitutes for tree nests; frequent social contact with other chimpanzees and human caregivers; opportunity to establish close social bonds in groups of mixed age and sex; variety in basic routine, including diet, social interaction, and object manipulation; and presence of intellectual stimulation and challenge.

It is precisely because chimpanzees are so like humans physiologically that they are used by medical researchers in the attempt to alleviate human suffering and illness. And it is also because they are so like ourselves emotionally, cognitively and behaviorally that we must improve the quality of their lives during those long years of imprisonment and servitude.

In order to assist the USDA in formulating regulations that are in keeping with the spirit of the new legislation on psychological well-being for chimpanzees and other primates held in captive conditions, we offer the following recommendations:

A.GENERAL ISSUES

Scientists intending to perform experiments on chimpanzees must be able to prove, beyond all reasonable doubt, that the experimentation cannot be performed by using a lower species, via non-animal alternative methods, or through carefully controlled clinical research. Chimpanzees should only be used for laboratory research of exceptional importance. All proposals for work involving chimpanzees must be subject to rigorous and independent professional scrutiny, with due consideration of whether similar studies have been undertaken previously or are already in progress elsewhere. Evaluation of the scientific merit of the proposed work and the benefits likely to accrue from it must be set against the likely adverse effects on the chimpanzees to be used. Unnecessary and unjustified duplication of experimentation is scientifically and ethically unacceptable, as are terminal studies on chimpanzees. Once a project using chimpanzees has been approved by the proper authorites, changes in protocol that potentially affect the psychological well-being of the experimental subjects must be periodically reviewed and reapproved under the same set of standards.

The use of chimpanzees in laboratory research is an international problem, and should not be considered solely in a national context. It is deemed unacceptable for individual scientists, institutions, corporations, or funding agencies to be involved in research on chimpanzees carried out in other countries having lower standards of scientific scrutiny or animal housing, care and acquisition. Moreover, the taking of chimpanzess from Africa for any reason is unacceptable.

Any chimpanzee used once for painful and/or extremely stressful experimentation should be exempt from further experimentation of a painful or stressful nature.

B. PERSONNEL TRAINING

Scientists whose work involves the use of chimpanzees for any purpose must have an understanding of the nature of chimpanzees, so that the effects of experimental protocols on individual chimpanzees can be properly assessed in the course of planning the research.

Caregivers responsible for chimpanzees must receive special training, over and above the standard training required in caring for other laboratory species, including other primates, to fit them for the very special task of attending to the physical and psychological needs of chimpanzees. These special training procedures must be established at every facility housing chimpanzees. Evidence must be provided that training has been undertaken and successfully completed. In addition, a national accreditation scheme must be established, providing for professional certification by the USDA. The National Agriculture Library, in cooperation with the National Library of Medicine, should facilitate training by providing manuals, videotapes and other books and papers that must be read by those working with chimpanzees.

During the selection of caregivers, emphasis must be placed on the qualities of compassion, dedication, and empathy with chimpanzees, in addition to the usual qualifications demanded of such laboratory personnel. The adult chimpanzee to caregiver ratio must never fall below ten to one. With youngsters below the age of 7 years, additional caregivers are required in order to maintain frequent interaction.

The director of any facility must be responsible for ensuring that all institution personnel, including caregivers, are fully aware of the rules and regulations of USDA Veterinary Services and other pertinent governmental agencies that apply to the maintenance and experimental use of chimpanzees. Any violations of these regulations must be reported to the USDA and any funding agency involved.

C. HOUSING CONDITIONS

Chimpanzees must be kept in compatible groups, at a minimum two individuals together. Separation from close companions typically induces pyschological stress leading to physiological as well as behavioral changes, and in addition to threatening well-being may skew the results of experiments performed on that individual.

Chimpanzees must never be housed singly unless sick and in need of special treatment. If under exceptional circumstances the experimental protocol necessitates single housing, then the scientist must prove the need for this beyond all reasonable doubt. There is no known or justifiable medical or scientific reason for a chimpanzee to be kept in an isolette -- i.e., a chimpanzee must never be maintained without aural and visual contact with other members of the same species, on at least two sides of the enclosure.

Chimpanzees must be housed in areas of not less than 400 square feet, with a minimum height of 7 feet, consisting of two to four inter-connecting enclosures in different rooms. The structure and fur-nishings of the enclosure must provide ample opportunity for vigorous activity as well as privacy, and for varying the size of the social group.

The size of enclosures should increase on a sliding scale as a function of the number of chimpanzees being housed in a group. Two adult chimpanzees require 400 square feet of usable space, but in cases of demonstrated compatibility four adults or six juveniles can be maintained in enclosures of this size. If a scientist can confirm an empirical need for individual housing for experimental purposes, the enclosures must never be smaller than 196 square feet (14 ft. x 14 ft.) with as much height as is reasonably possible within a standard room (minimum 7 feet).

In all newly built facilities chimpanzees must be provided with an outdoor activity area. Chimpanzees should never be confined to rooms without windows through which to view the outdoors.

Existing facilities which cannot immediately comply with the new regulations pertaining to enclosure size must nevertheless provide chimpanzees with exercise rooms of 200 square feet floor area until the abovementioned standards can be fully implemented.

D. ENVIRONMENTAL FACTORS

Chimpanzees must be provided with a variety of occupations and opportunities for object manipulation in the effort to improve their lives of confinement to the greatest extent possible. This must include variety in food items, variation of routine with surprise treats and events, provision of items such as magazines, empty egg cartons, etc. A series of problems solving devices will enable them to work for their food instead of picking it out of a feeder bin. They must be given the opportunity to exercise some control over their environment. As an example, a series of buttons, connected to a computer terminal, can provide, when pushed, a drink, a raisin, a toy, etc. Such machines could be activated at irregular times and the chimpanzees informed by a caregiver or some signal device. Detailed records must be kept of the different enrichment procedures used each day, and made available to USDA (APHIS) inspectors. A regular exchange of information about enrichment procedures should also be promoted among facilities.

Mechanical enrichment devices or procedures, such as those noted above, should not be regarded as substitutes for social activity with caregivers.

Bedding materials, such as blankets, are essential. Young chimpanzees can readily be taught to hand over such items in the morning, for washing, in exchange for, for example, a treat.

Handling procedures such as anesthetization, capture, introductions, moving to new enclosures must be done in ways that minimize stress, fear, and physical harm. For example, chimpanzees living in large cages can be taught to enter smaller separate handling cages for experimental procedures, such as injections. If chimpanzees routinely sleep in small cages attached to the larger enclosures they can then be easily handled in the morning if needed for experimental purposes.

For young chimpanzees, friendly interaction with the caregiver is also of tremendous importance, and must be encouraged on a regular basis so as to develop bonds which help to reduce stress when individuals must be handled in experimental protocols.

The Institutional Animal Care and Use Committee shall establish, in consultation with the attending veterinarian, written procedures and guidelines for ensuring the psychological well-being of primates in accordance with established regulations and standards, and a record system to permit evaluation of compliance.

E. SOCIAL CARE FACTORS

The mother-infant bond is essential to normal pyschological development of an infant chimpanzee. In addition, relationships with other chimpanzees during infancy lead to the acquisition of normal social and parental skills. Therefore, every effort must be made to raise infants in multi-mother groups that also include compatible adult males.

Infants must remain with their mothers as long as possible, at least to the age of 18 months. If earlier separation is necessary because the mother is unable to care for the infant, fostering of the infant to another lactating female should be attempted. If that is not possible, the infant must be placed with compatible youngsters of similar age. Infants under the age of 18 months who are separated from their mothers and raised by human caregivers must receive individual care around the clock for several months. When mother-infant separation is required by experimental protocol, this should be done so as to provide time for the gradual transfer of emotional attachment from the mother to the human caregivers.

Youngsters of any age who are separated from their social groups for use in any experiment must be given a minimum period of 3 months for adjustment to their new conditions, before placement in any experimental situation.

Careful attempts must be made to reunite juveniles and infants with their mothers in their original social group at the completion of experiments.

F. RELOCATION

The transfer of chimpanzees between research facilities should be avoided unless absolutely necessary. If it becomes necessary to relocate individuals or groups, then chimpanzees should be accompanied by a familar caregiver who must remain with them until they have begun to adjust to the new facility and formed new affinitive attachments with the new caregivers.

G. RETIREMENT

Chimpanzees who are no longer useful to biomedical research must be retired and when necessary rehabilitated so that they may live out their lives in conditions that guarantee their psychological well-being until they die of natural causes. No research projects involving the experimental use of chimpanzees should be initiated without prior guarantee of adequate funding to endow a program of retirement designed to provide normal lifetime support for each subject.

H. SCHEDULE OF IMPLEMENTATION

In order to comply with these standards, it is expected that all facilities housing chimpanzees will require extensive modification. Implementation of the new standards in a graded sequence, with some changes expected to occur immediately while others may require months or years to complete after publication of the new regulations. All facilities must submit their plans for implementation within six months to the USDA. Basic enrichment programs which involve little or no cost should be implemented immediately. Temporary improvements to existing enclosures, such a joining tunnels and exercise rooms, must be implemented within one year. More extensive reconstruction or erection of new enclosures must occur within five years. Construction projects that are currently underway must be immediately modified to conform to the new standards.

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Senator MELCHER. Well, I have a very keen interest in working out whatever the hangups are on the regulations.

I was a little bit surprised to have Dr. King mention while reading Dr. Hunt's testimony, that the regulations, proposed regulations on psychological well-being of primates, were unacceptable. I have not seen what is being proposed right now.

I have an idea that over the long run we will have to phase in these regulations. Do you share that view?

Ms. STEVENS. Yes; of course my testimony, that is in the record, is asking for funds to make that possible.

Obviously what you say is correct. There should be funds for that specific purpose. Many scientists have claimed that the only way that funds to improve conditions for laboratory animals could be obtained would be to take that money away from research.

First of all, that is not true. Second of all, it should not be true. This is something that Congress has asked for that the American people are eager to see happen, and the money should be appropriated for that specific purpose.

Senator MELCHER. Yes; I think we ought to separate that out to begin with.

The argument, well, if they do this, taking better care of the laboratory animals, you are going to have less research. That may, from the practical standpoint be true, unless Congress does face the point that this is a separate issue.

We want the same level of research, which I do, then I think the answer is that there must be other money appropriated, and perhaps to upgrade the facilities. When we come to psychological well-being of primates, I have always recognized that in order to comply with that requirement in the law, that it would require changes in the facilities where research is done using primates as the laboratory animal subject.

We did not authorize any additional money when we passed it. We just implied that additional money would be necessary. I think we have to make it very clear in the appropriation process that indeed it is additional money if we want to maintain the same level of research that we have had in the past. And I do want to maintain that level of research.

I do not know how much money we are talking about. That is another matter that we have not been able to get a handle on, and I guess until people see what the regulations are and the phasing in of those regulations, those requirements are, there is no way of talking about money.

But I think, am I correct, Christine, that the regulations should be finalized now. And then we can begin talking about how much money.

Ms. STEVENS. People do not even know what is going to be proposed under the psychological well-being. They are at sea. They have no idea. They say they might have to spend an immense amount of money.

However, there has been a lot in the literature recently showing that many improvements for the housing of primates are not expensive. For example, putting branches into cages. Putting two monkeys together instead of keeping them separately. Those things do not cost anything at all, and yet they are being held up by these obstacles continually being put out.

Also, you have to remember that it is not just the quantity of the research but the quality. And primates are very likely to suffer from lack of well-being to the extent that their physiological reactions are different, and they will be producing experimental results that will not be able to be verified or replicated.

So it is vital that the law be enforced and have the regulations so that people know exactly what they are going to be required to do.

Senator MELCHER. I think you are correct. And I will be talking again with Dr. Glosser who has been working on this even before he was appointed Administrator of APHIS. But we will see what we can produce in terms of the proposed regulations to get them before the public.

It is time now. It is past time really. We have waited 2 years to see what these regulations are going to be. And I think it is time now for review by those of us who are interested in the matter. Thank you very much, Christine.

Ms. STEVENS. Thank you, Mr. Chairman.

STATEMENT OF DR. LEON JACOBS, CHAIRMAN, BOARD OF DIRECTORS, AND PRESIDENT, GORGAS MEMORIAL INSTITUTE OF TROPICAL AND PREVENTIVE MEDICINE

Senator MELCHER. We will hear testimony now on the Fogarty International Center, Leon Jacobs, Dr. Jacobs, who is chairman of the board of directors of the Gorgas Memorial Institute. Dr. Jacobs?

Dr. JACOBS. Thank you, Senator Melcher. My testimony is really concerning the Gorgas Memorial Institute of Tropical and Preventive Medicine, which receives its appropriation through the Fogarty International Center of the National Institutes of Health.

I have already prepared and submitted to the subcommittee a statement concerning the Gorgas Memorial Institute [GMI] and its needs, and I merely want to emphasize in this testimony certain points regarding the relationship between GMI and the NIH.

The mission of the Gorgas Memorial Laboratory in Panama, which is the main focus of attention of the Gorgas Memorial Institute, is the study, surveillance, and control of prevention of diseases that are essentially prevalent in tropical conditions, in tropical areas.

This does not mean that they do not occur in other areas, but they offer a special opportunity and special problems in the tropical areas.

The GMI was established under the auspices of the Congress and the Republic of Panama in 1921. The GML, the laboratory, opened in 1928 in a building that was donated by Panama.

GMI has been supported by a contribution from the United States Congress, and with help from Panama. I have to tell you that the help from Panama is not inconsiderable in relation to the respective populations of the countries of the United States and Panama and their gross national products.

In addition to funding, we also get help in the form of customs exemptions, tax relief, and the provision of personnel from the Ministry of Health in Panama. GML has had a distinguished record of discovery of important facets of diseases such as yellow fever, malaria, viral encephalitis, and others in relation to their reservoirs in nature, transmitting agents, methods of disease production, and curative mechanisms.

In 1983, studies by the General Accounting Office and by the Office of Technology Assessment of the Congress, both of which were requested by this subcommittee, indicated that the laboratory should continue to receive support, and certain deficiencies that were noted were in such aspects as peer review and in administration and private fundraising.

PREPARED STATEMENT

We have made many corrections in that and our peer review of the scientific operations is modeled after that of the intramural program of the NIH. And we are attempting as best as we can to raise money elsewhere, but there is a complacency about tropical diseases in this country in between wars, and it is very difficult to get any fundraising accomplished.

I see my time is up. I would be happy to answer any questions if there are any. Thank you.

Senator HARKIN [presiding]. Thank you very much for your testimony. I was just getting briefed by counsel on the Gorgas Memorial Institute, and was looking over your testimony. We appreciate your being here and for giving us your views on this. I have no questions. Thank you very much.

[The statement follows:]

STATEMENT OF DR. LEON JACOBS

Thank you for the opportunity to present this statement concerning the contribution of the United States to the Gorgas Memorial Institute (GMI) for the maintenance and operation of the Gorgas Memorial Laboratory (GML) in Panama. I am especially grateful for the chance to clarify some questions which you, Mr. Chairman, raised about GMI/GML during the hearings on NIH before this Subcommittee on 26 April, regarding the Fogarty International Center.

The annual contribution to Gorgas, as you know, is authorized by P.L. 70-350 as amended. At present, the authorization is $2,000,000 and the funds are now provided to Gorgas thru the Fogarty International Center of the NIH.

As I pointed out in a similar statement to this Subcommittee last year, the Republic of Panama also makes contributions to the Gorgas Memorial Laboratory operation. The sum of $10,000 is provided annually. This is not an insignificant amount when it is considered in the perspective of the relative populations and gross national products of Panama and the United States. This year, we cannot anticipate receiving the complete amount because of the political and economic disturbances. However, the other forms of Panamanian support to the Laboratory do continue, such as customs and tax exemptions, and the provision of physicians and technical personnel paid by the Health Ministry and assigned to GML projects. This support is not inconsiderable.

It is five years, now, since the Gorgas Memorial Laboratory was rescued from certain demise by the action of the appropriations committees of the Congress, after GMI/GML was included in a proposal by NIH to eliminate various types of center grants. (The inclusion of GMI/GML with NIH center grants was inappropriate, because the legislative authorizations are completely different.) This Subcommittee, then chaired by Senator Weicker, requested studies by the General Accounting Office and by the Office of Technology Assessment, to serve as bases for a decision on continued congressional contributions for GMI/GML. The reports of these studies, while recording various deficiencies that needed correction or improvement, recommended that GMI/GML be provided with funds for their continued existence. GMI was directed by the Senate report, No. 98-247, to respond to the criticisms expressed by GAO and OTA. There followed two letters which I addressed to Senator Weicker on 27 January 1984 and 15 March 1984, outlining actions taken and planned by GMI. I have copies of this correspondence to supply for the record or to be cited in the record.

The gist of the questions you addressed to Dr. Kupfer on 26 April related to peer review and oversight of the activities of GMI/GML. You also asked for details of funding of individual projects. I believe it is worthwhile now to give you an outline of changes and improvements that have occurred in our operations since the responses to criticism cited above.

In order to implement the recommendations that there be more formal and effective peer review mechanisms, GMI has used its Advisory Scientific Board (ASB), consisting of 36 scientists many of whom also serve on NIH review panels and/or advisory councils, and other consultants in the following ways:

1. In November 1984 and August 1985, Fogarty sponsored and participated in site visits to the GML to examine the programs in parasitology and in virology and epidemiology. Shortly after the second site visit, GMI called a meeting of its Advisory Scientific Board members in the related fields of interest. The meeting was held in Washington, D.C. with participation of Fogarty personnel, and the site visit reports served as the bases for the discussions. An attempt was made to come to a better definition of the role of small out-lying laboratories such as GML, as to the extent to which their special opportunities for field work can be exploited more with the adaptation of new sophisticated biotechnological procedures. Other important discussion items included the mechanisms for keeping the ASB members apprised of GML programs and utilizing their expertise in technical reviews of projects.

2. We have adopted the procedure of having scientific papers, in draft form, submitted by GML staff to GMI, for distribution to at least two reviewers on GMI's Advisory Scientific Board prior to submission in final form to a journal for publication. This procedure serves several purposes: a) It involves the ASB members in review not only of projects but of programs; b) it provides a way for the ASB members to participate in evaluation of the GML work and product; c) it ensures high quality in

the papers that GML does send for publication; and d) it provides an opportunity for ASB members to offer suggestions for future work.

3. A new Director of the Gorgas Memorial Laboratory was appointed on August 1, 1987. He is William C. Reeves, M.D., whose curriculum vitae is attached for the record. Dr. Reeves is a bilingual, productive investigator with administrative skills, who has served the Laboratory during the past 10 years as Chief of GML's Division of Epidemiology. He has personally competed successfully in seeking grants and contracts and is today the principal investigator of three important GML projects supported with such funds.

In the interim between Directors and under Acting Director Rolando Saenz, M.D., the GML scientific staff conducted an evaluation of those activities being supported by core funds. This led to the elimination of some costly and poorly productive projects. The current GML staff now participates regularly in the evaluation of projects, programs and budgets before they are submitted to GMI for review. Director Reeves has prepared a scientific staff evaluation program to which all scientific staff have subscribed; it calls for a routine annual evaluation by the Director and Division Chiefs to assure adequate orientation and performance, followed by a formal biennial review by the Director and outside reviewers to assess scientific competence and merit to GML, and to recommend (or not) continued tenure at GML or advances in pay status. Dr. Reeves also proposes to involve more ASB reviewers in examination of GML work by bringing GML staff to discuss programs at large meetings to be held in the United States.

Several months ago, I began to explore with FIC the suggestions of another GML review, either here or in Panama, but the changes in FIC leadership at that time made discussions impractical. I do want to emphasize, however, that GMI/GML is perfectly willing to have FIC participate in evaluating our programs; we believe that this is necessary if FIC is to present our budget requests to the Congress. We are ourselves, we believe, to be held responsible for developing our programs and executing them, but appraisals of our performance are helpful and welcome.

I hope that this explanation of peer review of GML may allay any disquietudes about a failure on our part to submit to criticism or to be insensitive to the need for change. As we now stand, the GML is trimmer than before, as the result of the scrutiny that we have given to projects. We have lost some personnel because of this, but we expect to be able to recruit new investigators, with competences to handle some problems at a more sophisticated level. To accomplish this, however, we need our financial base restored. This base is the annual contribution provided under P.L. 70-350 which has been eroded in the last two consecutive fiscal years by the Gramm-Rudman-Hollings reductions. Let me remind the Committee at this time that the Gorgas Memorial Laboratory is a free-standing laboratory. The total staff numbers 110 of whom 10-12 are "full-time-equivalent" scientists; the rest are technicians, maintenance and administrative personnel. Approximately 73% of the core budget covers administrative and service expenses, including fixed payroll costs. The service work consists of the continual surveillance of the occurrence of diseases such as drug-resistant malaria, yellow fever, and viral encephalitis. This ought to explain why a U.S. contribution to core support is necessary. We are almost a unique resource in the Caribbean area. The only other tropical disease laboratory in the region is the Pedro Kouri Laboratory in Cuba which is supported, at least in part, by funds provided by France. GML must make provision, when we hire U.S. scientists, for transportation costs and other expenses. Moreover, in consonance with the recommendations in the OTA and GAO reports, we have to provide our new personnel with new and expensive equipment.

We are, indeed, making use of new aspects of biotechnology. For example, the only way to identify human papillomavirus types is by the use of DNA probes, because the virus has not been cultivated yet. We do this work at GML. We are seeking private donations to support the acquisition of new equipment and the refurbishing of our laboratories in order to support this new technology. We have been advised by a fund-raising consultant that we have little chance of obtaining sustaining endowments because exotic diseases attract little interest here, but that we might be more successful on a project, or instrument, basis. We have just received our first contribution in recent years from a private Panamanian source: $20,000 from the husband of the late Elena Maduro de Fidanque, for studies in clinical disease. We are working to get similar contributions from U.S. donors.

There are additional changes we have made in our organization and activities, which may be found in the annual report submitted to the Congress in April of this year. After a 3-year trial, we have given up the services of a paid Chief Executive Officer/President. I am serving pro *bono* in that capacity as well as Chairman of the Board. All of the Board members also serve without compensation. The Gorgas Memorial Institute is dedicated to maintaining the GML as a center of competence in tropical medicine within the Central American region. To this end, we request that the GMI/GML be supported through the Fogarty International Center in F.Y. 1989 at the level of $2,000,000 as authorized by P.L. 70-350 as amended.

Thank you very much, Mr. Chairman.

CURRICULUM VITAE

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Washington, D.C. 20015

Phone: 202/966-2674

Date and Place of Birth:

March 26, 1915
Brooklyn, New York

Educational Background:

Boys High School Brooklyn, New York		1927-1931
Brooklyn College Brooklyn, New York	B.A.	1931-1935
George Washington University Washington, D.C.	M.A.	1936-1938
George Washington University Washington, D.C.	Ph.D.	1939-1943 1946-1947
Tissue Culture Course, Mary Imogene Bassett Hospital, Cooperstown, New York		7/49-9/49
Course in Virology, U.S. Department of Agriculture Graduate School, Washington, D.C.		1949
Course in Ophthalmic Pathology, Armed Forces Institute of Pathology, Washington, D.C.		2/9-13/53
Course in Pathology, U.S. Department of Agriculture Graduate School, Washington, D.C.		1953
Course in Veterinary Pathology, Armed Forces Institute of Pathology, Washington, D.C.		1959

Professional Experience:

Junior Nematologist to Protozoologist, Division of Zoology, NIH	1937-1943
United States Army	1943-1946
Protozoologist to Scientist Director, NIAID, NIH	1946-1956
Head, Section of Protozoal Diseases, Laboratory of Tropical Diseases, NIAID, NIH	1956-1959
Chief, Laboratory of Parasitic Diseases, NIAID, NIH	1959-1964
Acting Scientific Director, NIAID, NIH	1964-1965
Scientific Director, DBS, NIH	1966-1967
Deputy Assistant Secretary for Science, DHEW	1967-1969
Assistant Director for Collaborative Research, NIH	1969-1972
Associate Director for Collaborative Research, NIH	1972-1978
Director, Fogarty International Center, NIH	1978-1979
Visiting Prof. of Microbiology, University of Arizona Medical School	1979-1981
Visiting Prof. of Microbiology, University of So. Florida Medical School	1980-1982
Scientific Director, National Society for Medical Research, Washington, D.C.	1981-1982
Scientific Consultant, National Society for Medical Research, Washington, D.C.	1983- 1985

Membership in Scientific Societies:

American Society of Tropical Medicine and Hygiene	
Editor, *Tropical Medicine News*	1952-1955
Representative to National Research Council	1957-1961
Council	1964-1968
Vice President	1970
American Society of Parasitologists	
Editor, *Journal of Parasitology*	1955-1958
Chairman, Committee on Business Operations	1959-1960
Council	1963-1966
President	1978
American Association of Immunologists	1956-1980
Helminthological Society of Washington, President	1950
Tropical Medicine Society of Washington, President	1971
Society of Protozoologists	1955-1980
American Association for the Advancement of Science	
Sigma Xi	
New York Academy of Sciences	

Research Interests:

Cultivation, epidemiology, and pathogenicity of parasitic protozoa; immunology and serology of protozoan and helminthic infections. Particularly interested in toxoplasmosis (life cycle and epidemiology, immunity, diagnostic procedures, ocular and other clinical manifestations and serology.)

Professional Publications:

Bibliography attached.

Other Activities:

Lectures at Johns Hopkins University School of Hygiene and Public Health	1956-1986
Lectures at Georgetown University Medical School	1965-1968
Lectures and laboratory teaching of parasitology at Western Reserve University Medical School	1954-1958
Representative of the American Society of Tropical Medicine and Hygiene to the National Research Council	1957-1961
Consultant, Committee on Uveitis, American Academy of Ophthalmology and Otolaryngology	1957-1958
Chairman, Committee on Cooperative Publication, Conference of Biological Editors	1958-1960
Director and member of Executive Committee, Gorgas Memorial Institute	1969-1979
Chairman, Toxoplasmosis Sessions, 7th International Congresses on Tropical Medicine and Malaria	1963
Member, Executive Committee, Commissioned Officers Association of the U.S. Public Health Service	6/65
Member, WHO Expert Panel on Parasitic Diseases	1956-1976
Chairman, Panel on Parasitic Diseases, U.S.-Japan Cooperative Medical Science Program	1965-1970
Member, Microbiology Subcommittee, Safe Drinking Water Committee, National Academy of Sciences	1976-1977
Chairman, Subcommittee on Research, U.S-Egypt Joint Health Working Group	1977-1979
Member, Board of Directors, Gorgas Memorial Institute of Tropical and Preventive Medicine, Incorporated	1969-
President and Chairman of the Board, Gorgas Memorial Institute of Tropical and Preventive Medicine, Incorporated	1983-85
Chairman of the Board, Gorgas Memorial Institute of Tropical and Preventive Medicine, Incorporated	1985-
Adjunct Professor of Preventive Medicine, USUHS	1985-

Honors and Awards:

Army Commendation Ribbon	1945
Past President, Helminthological Society of Washington	
Biological Sciences Award of the Washington Academy of Sciences	1954
Arthur S. Flemming Award of the Junior Chamber of Commerce	1954
Brooklyn College Distinguished Alumnus Award	1955
Barnett Cohen Award, Maryland Society of Bacteriologists	1956
Fulbright Research Scholarship	1960-1961
Guggenheim Fellowship	1960-1961
Council, American Society of Parasitologists	1963-1966

Henry Baldwin Ward Medal of the American Society of Parasitologists	1963
George Washington University Alumni Achievement Award	1967
Distinguished Service Medal, USPHS	1966
Superior Service Award, DHEW	1968
Vice President, American Society of Tropical Medicine & Hygiene	1970
President, American Society of Parasitologists	1978

STATEMENT OF DR. MYRON WEISFELDT, PRESIDENT-ELECT, AMERICAN HEART ASSOCIATION

Senator HARKIN. The next witness is Dr. Myron Weisfeldt, president-elect of the American Heart Association. Welcome to the subcommittee, Dr. Weisfeldt. And I am sure that it has already been requested that the statements will be made a part of the record. Please proceed.

Dr. WEISFELDT. Thank you, Senator Harkin. I am Myron Weisfeldt. I am director of the Cardiology Division of Johns Hopkins and designated as president-elect of the American Heart Association.

It is my pleasure to provide you with the American Heart Association's comments on funding and recommendations for the National Heart, Lung and Blood Institute, where I serve as chairman of their Cardiology Advisory Committee.

Cardiovascular disease remains America's No. 1 killer. Approximately 1 million people in the United States die each year from heart attacks, strokes, and related diseases.

In 1987 the total economic costs associated with cardiovascular disease are estimated to be over $80 billion in direct medical expenses and lost output due to disability and death.

While the American Heart Association continues to devote a large portion of its resources to research, sufficient funds for Federal biomedical research are critical. The President's fiscal year budget with AIDS includes $1.055 billion for the NHLBI.

The programmatic impact of this budget would stifle the NHLBI's research efforts in a number of respects. First, only 828 competing research project grants could be funded, a decrease of 17 percent from fiscal year 1988 estimates.

Research career programs and research training would receive only a 2-percent increase over the fiscal year 1988 amount for the same number of awards. Research centers and research and development contracts would be held constant for non-AIDS activity adversely affecting cardiovascular centers and postponing planned new clinical trials, including the artificial heart program.

In the early 1960's we went about two goals, one in space and one creating the artificial heart. We have succeeded in one of these two objectives only.

We would like to highlight three of the NHLBI programs for further comment. The NHLBI program of excellence in molecular biology initiative in fiscal year 1988 integrates these technologies into cardiovascular and pulmonary research.

These programs hold great promise for significant scientific advancement. The AHA has created some of the enthusiasm in the cardiovascular community for molecular biology through the AHA-Bugher Foundation Centers for Molecular Biology in the cardiovascular system.

The NHLBI's National High Blood Pressure Education Program and its National Cholesterol Education Program are prime examples of successful public and private cooperative efforts.

These highly visible programs significantly impact on public health and complement the AHA's Heart Rx program, and our Physicians' Cholesterol Education Program.

AHA supports purchases of state-of-the-art imaging devices for the NHLBI intramural program in their new laboratory for cardiac energetics designed to obtain more information on the heart cellular processes.

These data will lead to further improvements in the prevention, diagnosis, and treatment of cardiovascular diseases. The research, prevention, and educational programs of both the NHLBI and the AHA have made significant strides in the battle against cardiovascular disease.

From 1976 to 1986 the death rate from coronary artery disease has declined by 27.9 percent, and that from stroke has fallen by 40.2 percent. The future holds the potential for even greater progress. However, continued research productivity depends upon sufficient support from the Congress.

PREPARED STATEMENT

Based on review of the NHLBI's critical needs, the American Heart Association recommends a fiscal year appropriation of $1.187 billion for the NHLBI. This level of funding constitutes a 23-percent increase over the fiscal year 1988 appropriations. Thank you very much, Senator Harkin.

[The statement follows:]

STATEMENT OF DR. MYRON WEISFELDT

I am Myron Weisfeldt, director of the Cardiology Division at the Johns Hopkins Hospital and president-elect of the American Heart Association (AHA). The AHA is dedicated to the reduction of premature death and disability from cardiovascular diseases and stroke. In reaching our goal, we work closely with federal research, education and prevention programs whose objectives are similar to ours. The AHA and the National Heart, Lung and Blood Institute (NHLBI) work in active partnership in the battle against cardiovascular diseases--still this Nation's leading cause of death. It is my pleasure to provide you with our comments and funding recommendations for the NHLBI.

Approximately one million people in the United States die each year from cardiovascular diseases. Of the current United States population of approximately 239 million, nearly 65 million suffer some form of cardiovascular disease. Moreover, in 1987, we estimate the cost associated with these diseases to be over $80 billion in direct medical expenses and lost output due to disability and death. However, progress is being made. From 1976 to 1986 the death rate from coronary heart disease has declined by 27.9% and that from stroke has fallen by 40.2%.

Throughout our 40-year partnership the research, training, education, and community service programs of both the AHA and the NHLBI have had a significant impact on diseases of the heart and circulatory system. The NHLBI's National High Blood Pressure Education Program and its National Cholesterol Education Program are prime examples of successful public and private cooperative efforts. They complement AHA's recently launched educational initiatives in these areas: our "Heart RX" program and our "Physicians' Cholesterol Education Program."

AHA's ability to combat cardiovascular diseases directly correlates with the level and quality of overall support of basic and clinical research and prevention efforts. Sufficient funds for federal biomedical research are critical.

Before examining the President's FY 1989 budget, I will focus on several of our concerns about the Institute's current budget. A major interest is the level of support for the NHLBI as compared with the other Institutes. NHLBI's increase over its FY 1987 appropriation ranked them 10 out of 12 institutes. Since diseases of the heart, lung, and blood kill more Americans than all other diseases, we believe that the Institute's allocation of funds should reflect it. Although there are shortcomings in the President's FY 1989 budget request for NHLBI, we were pleased to note that the Administration has recognized the above fact; and under its request now ranks NHLBI first in percentage increases over its FY 1988 funding without AIDS.

Still a pending concern is the rising average cost of research grants. This increase is largely due to higher costs for equipment, personnel and patient care. Because the Institute sponsors an extensive amount of clinical research, these costs cannot be avoided. In light of these conditions, the NHLBI can only fund 855 competing research grants--111 fewer than in FY 1987. In addition, the Institute will be forced to reduce these grants downward possibly as much as 15%. Also, the downward negotiation for noncompeting grants may run as high as 10 to 11%.

Although each house in its respective committee report eloquently described the NHLBI's planned "Programs of Excellence in Molecular Biology"--integrating these technologies into cardiovascular and pulmonary research--no funds were provided for it. The NHLBI has received 19 applications for these programs but can only support three in FY 1988. Another competition is scheduled for FY 1989. Because these programs hold great promise for significant scientific advancements, AHA urges the Subcommittee to appropriate money for them. Our recommended FY 1989 appropriation level for the NHLBI includes funds (an additional $10 million) to adequately support these important programs. AHA was instrumental in developing some of the enthusiasm in the cardiovascular community about molecular biology through the AHA-Bugher Foundation Centers for Molecular Biology in the Cardiovascular System.

Finally, we were pleased to note that the Office of Management and Budget had agreed to apportion funds at the appropriation level. Also, we commend Congress' efforts in prohibiting the use of FY 1988 funds for forward funding or multiyear funding of research project grants except as determined by the NIH Director. However, AHA strongly believes that these two requirements should be made permanent.

Now, Mr. Chairman, I turn to the President's FY 1989 budget request for NHLBI. The numbers and dollar figures in this statement contain AIDS money. The President's FY 1989 budget includes $1.055 billion for the NHLBI. Although this budget represents a 9.2% increase in funding over the FY 1988 appropriation level, it does not support adequate growth. In addition, the programmatic impact of this proposed budget will stifle the NHLBI's research efforts. If this budget were enacted, the NHLBI would be forced to significantly change its programs and planned research initiatives.

Under the President's proposal, the Institute will be able to fund only 828 competing research project grants, a decrease of 17 from the FY 1988 estimate. Due to the growth in the cost of these grants, funding will have to be negotiated downward an average of 13.5%. The average cost of competing grants has increased 3.5% over the FY 1988 estimate. Moreover, funding for noncompeting research project grants will have to be reduced an average of 11.4%; their cost will rise about 4.6% over the FY 1988 estimate. These reductions are too high. An additional $22 million for the research grant mechanism will bring these reductions to a more acceptable level--9% for both competing and noncompeting grants.

The President's budget holds funding constant for non-AIDS activities in research centers; and under research and development contracts. In order to provide research centers with minimal flexibility in FY 1989, the Institute will need about $95 million--an additional $5 million. Although the President's budget calls for the same number of centers to be funded, it provides no additional non-AIDS money. The NHLBI's cardiovascular centers will be adversely affected if funds are not increased.

Also, the President's budget provides no non-AIDS increase for research and development contracts. The proposed amount for contracts ($89.205 million) is far below the level to maintain current and projected activities for FY 1989. An additional $5 million will be required. If contracts were funded at the level requested by the President, no new clinical trials will be supported. Specifically, several research contract programs in the cardiovascular area will be threatened. The continuation of the artificial heart program will be placed in jeopardy, and a clinical trial designed to determine whether HMG CoA reductase inhibitors (a new class of cholesterol-lowering drugs) will reduce death from atherosclerotic cardiovascular disease in older men and women will again be postponed.

In addition, under the President's budget, research career programs and research training will each receive only a 2% increase over FY 1988 for the same number of awards. A total amount of $31.807 million--an additional $5 million--is needed to keep research career programs competitive. To provide the Institute's research training program with minimal flexibility, an additional $2.2 million will be required for a total of $42.520 million.

The President's budget provides for an increase in both the NHLBI's intramural research, and research management and support (RMS). This increase in intramural research will support the new Laboratory of Cardiac Energetics designed to obtain more information on the heart's cellular processes. This data will lead to further improvements in the prevention, diagnosis and treatment of cardiovascular diseases. However, an additional $4 million to the intramural program will be required for the purchase of a state-of-the-art imaging device and subsequent laboratory renovations for its installation. Our recommended FY 1989 budget level includes funds for this device.

The Institute's education and direct prevention programs are supported primarily from two budget categories: 1) research and development contracts and 2) RMS. AHA is concerned about the level of support for the NHLBI's programs in this area. The NHLBI's highly visible National High Blood Pressure and National Cholesterol Education Programs are prime examples of successful public and private cooperative efforts. Our recommended funding level for NHLBI provides necessary increases (an additional $4 million) for these budget categories to enable the Institute to sufficiently support these efforts.

The programs of the NHLBI have been highly successful in the battle against cardiovascular diseases because of the valuable principle guiding the Institute--maintaining research program balance. While the cornerstone of its program is basic research, the Institute's staff, Advisory Council and the scientific community over the years have also stressed the importance of other program mechanisms including clinical trials, population studies, specialized centers for research (SCORS), national research and demonstration centers, research career and training awards and development contracts. This balanced program approach has enhanced the NHLBI's reputation as a world-wide leader in cardiovascular research. This is due to its rigorous peer review process.

Based on a review of NHLBI's critical needs outlined above, AHA recommends an increase of 23% above its FY 1988 appropriation, or an FY 1989 appropriation level of $1.187 billion for the NHLBI. This is consistent with the Ad Hoc Group For Medical Research Funding's suggested percentage increase for the entire National Institutes of Health (NIH).

The NIH is the leading biomedical research support agency of the federal government, and the NHLBI is the largest source of support for cardiovascular research. We believe that the President's budget for the NIH falls short of maintaining current services. The Ad Hoc Group For Medical Research Funding's FY 1989 recommendation for NIH of $8.2 billion is a 23% increase over the FY 1988 appropriations level. This increase for NIH will provide for a modest growth over its current services budget level and will allow for:

- funds to support 7,400 new and competing renewal research project grants;
- funds to increase research trainees to 11,350 (recommended by the NAS).

Senator HARKIN. How much of an increase are you asking for over last year?

Dr. WEISFELDT. Some 23 percent over the current year, fiscal year 1988.

Senator HARKIN. Counsel advises me our bill goes to 4 percent, the whole bill.

Dr. WEISFELDT. That will cut out essentially all new clinical trials in the heart disease area.

Senator HARKIN. Heart disease is still the largest killer?

Dr. WEISFELDT. Yes.

Senator HARKIN. And you say the AHA has recently launched an educational initiative called Physicians' Cholesterol Education Program. Is this program presenting new physicians about cholesterol?

Dr. WEISFELDT. Yes; it is a broad program. It involves training physicians as trainers as well as directly contacting physicians.

Senator HARKIN. Dr. Weisfeldt, are you familiar with S. 1109? Would you write it down and take it back to the American Heart Association so see if they would be interested in that piece of legislation? S. 1109. It involves labeling foods bought off the shelf, that contain saturated fat or not.

Dr. WEISFELDT. I understand.

Senator HARKIN. It has to do with tropical oils, palm oils, coconut oils, or soybean and corn oils, which are very low in saturated oils.

Dr. WEISFELDT. The American Heart Association is very concerned to provide the American public with a simple system for labeling so that when the consumer goes into the food store they can quickly identify those foods that have high content of saturated fat which they wish to avoid, and we wish them to avoid, and those food products which do not. And there is a number of strategies that we think will help, including obviously Federal legislation.

Senator HARKIN. While I have been in the past and will be in the future, very supportive of the National Heart, Lung and Blood Institute's programs, a lot of our problems have to do with education and getting people educated to eat the right foods, exercise and not smoke.

Dr. WEISFELDT. I am informed by my counsel that we have endorsed the bill.

Senator HARKIN. Thank you very much. I appreciate it. Do not feel badly. I cannot remember all the bill numbers either. So thank you very much, Doctor.

Senator HARKIN. Next is Ralph Cazzetta, Cooley's Anemia Foundation, Inc.

STATEMENT OF RALPH CAZZETTA, MEMBER, THALASSEMIA ACTION GROUP AND MEMBER, LEGISLATIVE COMMITTEE OF THE BOARD OF DIRECTORS, ON BEHALF OF COOLEY'S ANEMIA FOUNDATION

ACCOMPANIED BY LINDA DIPASQUAL, MEMBER, THALASSEMIA ACTION GROUP

Mr. CAZZETTA. Good morning, Senator Harkin. The 11th year that the representatives——

Senator HARKIN. I am sorry. Excuse me. Would you please identify yourself for the record?

Mr. CAZZETTA. Ralph Cazzetta from the Cooley's Anemia Foundation. And Linda DiPasqual is accompanying me.

Senator HARKIN. Thank you. Who is Nunzio Cazzetta?

Mr. CAZZETTA. That is my dad.

Senator HARKIN. Please proceed.

Mr. CAZZETTA. This is the 11th year that the representatives of the Cooley's Foundation have appeared before you.

We are pleased with the advances made in understanding and treatment of Cooley's Anemia made possible by the support your committee has provided for the various programs of the National Institutes of Health and the Maternal and Child Health Program at the Health Resources and Services Administration.

I am Ralph Cazzetta. With me is Linda DiPasqual. Both of us are members of the Thalassemia Action Group which we have established for thalassemia patients who are over 12 years old. I am also a member of the Legislative Committee of the Board of Directors of the Cooley's Anemia Foundation.

First we want to thank this committee for the outstanding supportive research into the disease and the treatment of patients with Cooley's Anemia you have always provided. The research you have funded has been carried out by the National Heart, Lung and Blood Institute and the National Institute of Diabetes and Digestive and Kidney Diseases.

The work the NIDDK has been doing under the leadership of Dr. Gary Striker and Dr. David Badman has been outstanding and is moving us ever close to the day when we will find a cure for the disease.

This year the NHLBI published its report, Cooley's Anemia Progress in Biology and Medicine, in response to the request of Congress. This is such a fine report that the Foundation has printed and distributed nearly 5,000 copies of it, both nationally and internationally.

In the interest of time I would like to paraphrase the statement which says that while patients with Cooley's Anemia are few in number they constitute a national resource. Results of studies of these patients and attempts to develop treatments have been applied to the management of acute iron poisoning, renal dialysis, cancer, and bone marrow graft-vs-host disease.

The report recommends that the financial and social burdens faced by Cooley's Anemia patients should in part be relieved by a special program.

We are deeply indebted to Congress for requesting this report to the NHLBI and for its preparation and publication, and especially to Dr. Claude Lenfant, director of the NHLBI for his vigorous and constant support.

At this time I also wish to recognize the support we have received from the Maternal and Child Health Program which funds the Cooley's Anemia centers. The services provided by these centers are critical and have contributed to the increased life expectancy of people with Cooley's Anemia.

We are greatly indebted to the Maternal and Child Health Program for their efficient management and stewardship of this activity.

Since Cooley's Anemia patients are dependent on frequent and regular blood transfusions to maintain life, we are concerned about the adequacy and safety of the country's blood supply, and therefore have a keen interest in transfusion medicine and advances that have occurred recently.

We strongly support the NHLBI's commitment to support innovative research in transfusion medicine that would expedite the development and application of new knowledge essential to ensuring an adequate supply of safe blood.

We are pleased we have recently been invited to become a member of the National Blood Resource Education Program Coordinating Committee. The purpose of this committee is to work with the NHLBI to ensure an adequate supply of safe blood.

The next area that we want to highlight and request funding for is the work that is currently under way at the NHLBI aimed at the development of new iron chelators.

If excess iron is permitted to accumulate in the body, it results in premature death. While drugs have extended the life expectancy of many patients, it is costly and must be injected into the body 8 to 10 hours every day.

Because of the discomfort and long hours of administration, patient compliance has suffered, resulting in premature death of some patients. There now appears to be an exciting breakthrough as a result of work being conducted at the Royal Free Medical School in London, England.

Senator HARKIN. We have to ask you to please summarize.

Mr. CAZZETTA. We have several recommendations to make for fiscal year 1989.

One, that the NHLBI be funded at a level of $1.187 billion and that the NIDDK be funded at a level of $680 million.

PREPARED STATEMENT

That the Maternal and Child Health Special Programs of National and Regional Significance be fully funded so that the support of existing centers can be continued and that the bill report from your committee specify that the Cooley's Anemia Centers be continued and, where appropriate, be expanded. Thank you, sir.

[The statement follows:]

STATEMENT OF RALPH CAZZETTA

Mr. Chairman, this is the eleventh year that representatives of the Cooley's Anemia Foundation have appeared before you. We are pleased with the advances made in the understanding and treatment of Cooley's Anemia made possible by the support your committee has provided for the various programs of the National Institutes of Health and the Maternal and Child Health Program at the Health Resources and Services Administration.

I am Ralph Cazzetta, a member of the Thalassemia Action Group which we have established for thalassemia patients who are over 12 years old. I am also a member of the Legislative Committee of the Board of Directors of the Cooley's Anemia Foundation.

It will be useful for you to have a brief description of the disease. Cooley's Anemia is a fatal blood disease that is passed from parent to child, normally striking children of Mediterranean-American parents, including those of Italian and Greek descent, as well as Syrian, Israeli, and other population groups. Recently, we have seen increases of the disease manifest itself in immigrants from Asia.

First, we want to thank this committee for the outstanding support of research into the disease and the treatment of patients with Cooley's Anemia you have always provided. The research you have funded has been carried out by the National Heart, Lung and Blood Institute (NHLBI) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The work the NIDDK has been doing under the leadership of Dr. Gary Striker and Dr. David Badman has been outstanding and is moving us ever close to the day when we will have a cure for the disease.

This year NHLBI published its report, "Cooley's Anemia Progress in Biology and Medicine", in response to the request of Congress. This is such a fine report that the Foundation has printed and distributed nearly 5,000 copies of it, both nationally and internationally. Mr. Chairman, I have copies of the report for you to review at your leisure. I especially would like to call to your attention a statement contained on page 61 of the report. In the interest of time I would like to paraphrase this statement which states that while patients with Cooley's Anemia are few in number, they constitute a national research resource. The results of studies of these patients and attempts to develop treatment therapies have been applied to the management of acute iron poisoning, renal dialysis, cancer, and bone marrow graft-vs-host disease. The report recommends that the financial and social burdens faced by Cooley's Anemia patients should in part be relieved by a special program.

Mr. Chairman, we are deeply indebted to the Congress for requesting this report to the NHLBI for its preparation and publication, and especially to Dr. Claude Lenfant, Director of the NHLBI, for his vigorous and constant support over the years.

At this time I also wish to recognize the support we have received from the Maternal and Child Health Program, which funds the Cooley's Anemia centers. These centers have provided excellent services to us and have made services available to some of us who would not otherwise have been able to receive them. These services are critical and have contributed to the increased life expectancy of people with Cooley's Anemia. We are greatly indebted to the Maternal and Child Health Program for their efficient management and stewardship of this activity, as we are indebted to you for providing the funds to make this activity a reality.

The continued support of the ongoing activities of NHLBI, NIDDK, and the MCH Program continue to be the highest priority of the Foundation's Legislative Committee. Within these programs there are several areas of special interest and significance to us at this time.

Since many Cooley's Anemia patients are dependent on frequent and regular blood transfusions to maintain life, we are concerned about the adequacy and safety of the country's blood supply, and therefore have a keen interest in transfusion medicine and the advances that have occurred recently. Transfusion medicine, as a discipline, has made significant strides in recent years. Recent scientific advances in transfusion medicine have changed transfusion practices and provided efficiency in blood resource management. The introduction of new screening procedures to prevent the transmission of human immunodeficiency virus (HIV) and other transfusion-transmitted viruses has improved transfusion safety. Research opportunities in transfusion medicine range from basic to clinical and include such diverse topics as the development of new blood products, methods to improve and assure stability and safety of these products, and ways to improve benefits and safety of transfusion. We strongly support NHLBI's commitment to support innovative research in transfusion medicine that would expedite the development and application of new knowledge essential to ensuring an adequate supply of safe blood and blood products to effectively treat Cooley's Anemia patients as well as all other patients in need.

We are pleased we have recently been invited to become a member of the NHLBI National Blood Resources Education Program Coordianting Committee. The purpose of this Committee is to work with NHLBI to insure an adequate supply of safe blood and blood components to meet the nation's needs and to insure that blood and blood components are transfused only when therapeutically appropriate. We are encouraged by the work that the Committee has already accomplished. We are confident that the Committee will make a major contribution to insure an adequate and safe blood supply. We support the full funding of the activities of this group as they continue their work over the next several years.

The next area that we want to highlight and to request funding for is the work that is currently under way at NHLBI aimed at the development of new iron chelators. Because of the need of Cooley's Anemia patients for blood transfusions throughout the year they suffer from a build up of iron in their vital organs. If excess iron is permitted to accumulate in the body it results in premature death. In the early 1960's a drug became available to remove excess iron from the body. While the drug has extended the life expectancy of many Cooley's Anemia patients, it is costly and must be injected into the body 8 to 10 hours every day. Because of the discomfort and long hours of administration, patient compliance has suffered resulting in the premature death of some patients. There now appears to be an exciting breakthrough as a result of work being conducted at the Royal Free Medical School in London, England. They are working on the development of an oral chelator that appears to be very promising which costs less than the present drug and which will eliminate the need for injection of the chelating agent. When an oral chelator becomes available it will make a major contribution to solving the problem of patient noncompliance with the required iron chelator regime and thereby save lives and extend life expectancy for Cooley's Anemia patient.

We are very pleased that NHLBI has instituted a program to support the development of iron chelators that will be effective, less costly, and easier to use. We are hopeful that the NHLBI will be able to support the work currently being done in London.

We have several recommendations to make for FY 1989:

1. That the NHLBI be funded at a level of $1.187 billion.
2. That the NIDDK be funded at a level of $680 million.
3. That the Maternal and Child Health Special Programs of National and Regional Significance be fully funded so that support of the existing Centers can be continued and that the bill report from your committee specify that the Cooley's Anemia Centers be continued and, where appropriate, be expanded.

Thank you for permitting me to appear before you. I will be pleased to answer any questions you may have.

Senator HARKIN. Mr. Cazzetta, thank you very much. Let me ask you, how much of the Cooley's Anemia Foundation did you receive from NIH last year?

Mr. CAZZETTA. I believe it was—we did not receive money last year, we received grants specifically for Cooley's anemia last year.

Senator HARKIN. Grants from NIH?

Mr. GRUPENHOFF. May I clarify for the record? I am John Grupenhoff and I am the Washington representative for this group.

The Cooley's Anemia Foundation itself has not received any money from the Federal Government at all. They are a not-for-profit organization. There have been grants made to a number of scientists through the normal NIH peer review procedure for research on Cooley's anemia.

Senator HARKIN. Research scientists that are working with the foundation?

Mr. GRUPENHOFF. Not with the foundation, through the normal peer review process from the NIH. The foundation itself collects funds and awards grants to scientists also. But not from funds from the NIH.

Senator HARKIN. Is there one place where most of this research is being done?

Mr. GRUPENHOFF. No; it is done by hematologists across the United States.

Senator HARKIN. Thank you very much. I appreciate your testimony.

STATEMENT OF DR. BARRY COLLER, HEMATOLOGY SECTION, DEPARTMENT OF MEDICINE, STATE UNIVERSITY OF NEW YORK AT STONY BROOK

Senator HARKIN. Next is Dr. Barry Coller, Department of Medicine, State University of New York at Stony Brook, representing the American Society of Hematology.

Dr. COLLER. Senator Harkin, I am appearing on behalf of the American Society of Hematology, whose members were the lead scientists on more than $128 million in NIH grants in fiscal year 1985.

Rather than review my written testimony, I thought I would tell you some oral testimony concerning my own research career, because I believe it highlights some of the general principles about the importance of NIH.

After 4 years of training in hematology and learning how to perform research at the intramural program in Bethesda of NIH, I moved to the State University of New York at Stony Brook, where I have continued my NIH-funded research for the past 12 years.

For the first 6 years, my research was confined to the basic mechanisms of blood platelet function. Those studies formed the basis of animal experiments I am now conducting with other NIH grantees in Wisconsin and Boston that indicate that the monoclonal antibodies produced by my laboratory may be more effective than aspirin in treating certain forms of heart attacks and strokes.

These antibodies have been licensed to an American biotechnology company that has already invested more than $10 million, and recently raised an additional $40 million for studies to perfect this therapy.

The following general principles are illustrated by my experience. One, the intramural NIH program is a unique resource for training physician scientists. Two, a sustained commitment of NIH support to basic research guarantees an expansion of the scientific information required for developing rational strategies for treating disease.

Three, the newer scientific technologies have unleashed an explosion of therapeutic opportunities. Four, the training of physician scientists is vital in assuring that this potential is realized.

Five, American biotechnology companies currently are world leaders in part because they can work with NIH-supported American scientists to develop new diagnostic and therapeutic products with worldwide markets. Six, American investors are eager to support promising biotechnology products.

An historical perspective is very useful, since it reminds us that medicine as a field only entered the scientific era some 100 years ago.

I believe that harnessing the extraordinary power of the scientific method to alleviate suffering from human disease is one of the seminal achievements of the human race. And at the heart of that achievement stands the National Institutes of Health, supported by the people of the United States.

PREPARED STATEMENT

Our goal this year, therefore, is to fund 40 percent of overall NIH-approved investigator initiated research grants. Thus I recommend appropriations for fiscal year 1988 of $1.187 billion for NHLBI, $2.08 billion for NCI, and $680 million for the NIDDK. Thank you.

[The statement follows:]

STATEMENT OF DR. BARRY COLLER

On behalf of the American Society of Hematology and its more than 3,000 members, I wish to thank you for the opportunity to present testimony before the Subcommittee again this year in connection with the legislation for the fiscal 1989 appropriations for the National Institutes of Health.

I am here today representing the American Society of Hematology. This Society is the only national organization of hematologists and is made up of physicians and biomedical scientists who are concerned with research, patient care and teaching as they relate to blood and diseases which affect the blood.

Before presenting our views about this legislation, I would like to express my gratitude to the members of this Committee and to the entire Congress for their strong support last year on behalf of biomedical research and hematology. We appreciate your long-standing commitment to the programs of the National Institutes of Health. Most importantly, we thank you for the strong support you have given to investigator-initiated research. The creative imagination of our nation's scientists represents one of our country's greatest natural resources. The support that you direct to these scientists provides the raw materials upon which their ideas will flourish. The resulting benefits are enormous and important to each and every one of us.

The blood consists of both cellular and fluid components, both of which are critical to maintaining many of life's processess. Blood flows through every organ of the body, and abnormalities of the blood can affect many organ systems. Therefore, research concerning the blood is supported by a number of institutes, particularly the National Heart, Lung and Blood Institute, the National Cancer Institute, and the National Institute of Diabetes, Digestive and Kidney Diseases. This spectrum of support has been most productive for hematology research and for the broad research mandates of the individual institutes. We feel strongly that each of these institutes should continue to direct funds for the support of blood research.

The acquired immune deficiency syndrome (AIDS) continues to be a life-threatening disorder of major concern to the blood research community. AIDS is a disease which is transmitted in blood by infection of the cellular constituents of the blood. The manifestations of AIDS are seen in the dysfunction of many organ systems. Hematologists have been among the scientists leading the way in AIDS research, and progress has been rapid and extensive. Scientists have identified and characterized the offending agent in AIDS. They have determined the major blood cell which the AIDS virus infects, the mechanisms by which the AIDS virus infects these cells and the alteration in blood cell function caused by the AIDS virus. Considerable progress has been made over the past year in understanding how the AIDS virus both attaches to and enters blood cells. Elucidation of the different components of the virus involved in blood cell attachment and penetration has provided investigators with potentially new approaches for interfering with the AIDS virus- blood cell interaction. Furthermore, scientists studying the blood cells of AIDS patients have recently determined that two types of blood cells are infected by the AIDS virus, lymphocytes and monocytes/macrophages. It appears that virus infection of blood monocytes/macrophages may be responsible for much of the disease transmission. The great progress in the understanding of AIDS made thus far is a credit to the organization of the NIH itself and to the strong partnership which exists between the NIH and the many scientists making up the biomedical research community. Vigorous support of individual investigator-oriented research should continue to supply new ideas and approaches leading to the control of this dreaded disorder.

The fluid and cellular constituents of the blood interact with the blood vessel wall causing coagulation of blood and thrombosis. This process, when not functioning properly, can lead to stroke in cerebrovascular disease and to heart attacks in coronary artery disease. Stroke and heart disease are two of our major causes of death. Our understanding of the molecular events involved in blood-blood vessel wall interactions are helping to lead to therapies which will control these devastating diseases. One recent advance is the availability of a naturally occuring reagent, tissue plasminogen activator, that is able to lyse and dissolve clots. The gene for tissue plasminogen activator produced by blood-vessel wall cells has been cloned, and this has led to the production of plasminogen activator for therapeutic use. Over the past year patients with blood clots have been treated successfully with this new thrombolytic therapy. Tissue plasminogen activator has been shown to be effective for dissolving blood clots in blocked coronary arteries following a heart attack (myocardial infarction). This work has resulted from coupling advances in our understanding of the function of blood vessel wall cells with our increased knowledge of molecular biology which permits study at the level of the gene.

Our advances in molecular biology also have paid major dividends in our ability to control anemia. Thirty years ago scientists discovered a human hormone, erythropoietin. Erythropoietin is a growth factor produced by the kidneys which stimulates the production of red blood cells in the bone marrow where they are normally produced. The natural production of erythropoietin is curtailed in kidney disease and several other disorders. About 85,000 Americans suffer from kidney failure and the accompanying decrease in red blood cells or anemia. Hematologists, using new concepts in molecular biology, developed a method to manufacture this human hormone and to administer it to anemic patients with kidney disease. This development should have a significant impact on treatment of anemia associated with end stage kidney disease. Patients with chronic kidney insufficiency require a total of about 300,000 units of red blood cells each year. Because erythropoietin corrects the anemia of kidney disease, its use should help conserve the national blood supply by reducing the need for red blood cell transfusion in these patients. This should increase the availability of blood to patients with other diseases. Blood availability is of major concern, because of the shortage caused by AIDS virus infection in the community.

Erythropoietin therapy also holds promise for the many patients with sickle cell disease in whom it stimulates the production of normal red blood cells and, thus, favorably influences the clinical course. Erythropoietin will likely also raise the blood count in patients with Cooley's anemia.

Erythropoietin therapy not only improves the quality of life of such patients with anemia but also provides important economic benefits.

Erythropoietin is only the first of several newly characterized blood growth hormones which are becoming available for patient use. Scientists using new molecular biology approaches have been able to clone the genes for several blood growth factors leading to their development for therapeutic trials. Several of these growth factors have already been shown to be effective in correcting deficiencies of other blood cells, such as white blood cells and platelets. Currently, scientists are working to make these naturally occurring growth factors available for the treatment of a wide range of blood disorders. Thus, our understanding and characterization of growth factors will likely lead to the availability of a new class of therapeutic reagents for human disease.

Our learning about how growth factors work has led to the identification of certain pathways that regulate both normal and abnormal cell growth and proliferation. A major new concept has evolved from these observations, which is that there exists in normal cells certain genes, termed oncogenes, that are normally involved in the production of these growth factors. Scientists have now learned that oncogenes are very carefully regulated in cells. The advances being made in understanding the regulation of these genes has made a major impact in our understanding of cancer and the biologic processes involved in the development of malignancy. Scientists have now determined that changes in the structure of these oncogenes or changes in the control of their expression can lead to malignant transformation and the development of cancer and leukemia. It is now believed that these oncogenes are probably critically important in the initiation and subsequent behavior of most human malignant tumors. Our continued understanding of growth factors and oncogenes and the mechanisms of their control, no doubt, will have a significant effect in our ability to control cancer.

These are a few of some of the important advances in hematology research. Increasingly difficult new questions are being approached with new molecular technology. This is a costly process. It is costly in dollars, and is costly in personal commitment. Our nation's investment in biomedical research has become an investment in the future health of our loved ones,. The investment has been in basic, investigator-initiated, non-directed, creative research. It is to this research that the energies of the NIH must be directed. The current success of this research and its promise of future successes are strong imperatives for support of NIH research at a level of no less than $8.237 billion for fiscal year 1989.

I hope that we have succeeded in explaining to you some of the important areas of ongoing research in hematology. All of us have been affected one way or the other by the spectrum of these diseases. As we talk about science and dollars, let us not lose sight of our goal-- to minimize pain and suffering and maximize the sense of health and well being of our citizens.

The American Society of Hematology makes the following recommendations, and expresses concerns as follows:

1. That appropriations for FY 1988 for the National Heart, Lung and Blood Institute, the National Cancer Institute and the National Institute of Diabetes and Digestive and Kidney Diseases be funded at the suggested levels indicated below.

NHLBI:	$1.187 billion
NCI:	$2.080 billion
NIDDK:	$680 million

Our goal is for 40% of overall NIH approved investigator-initiated research grants to be funded.

2. That blood transfusion centers, called for in the appropriation bill report language last year, be funded in FY 1988 at the peer review recommended level. This is particularly important because of the AIDS public health threat. The Society is concerned that there is an increasing shortage of blood because of AIDS and increased organ transplants. We recommend support for the NHLBI public education program in this area.

3. That AIDS funding be an add-on, and not taken from on-going research programs. It is important for the NHLBI and NIDDK budgets be maintained at the above suggested levels.

4. We recommend that support for the NIH budget for FY 1989 should be at the $8.237 billion level.

5. We thank the Committee for its participation in noting last year as the 40th anniversary of the National Heart, Lung and Blood Institute and in recognizing the extensive contributions to biomedical research sponsored by NHLBI over these 40 years.

Senator HARKIN. Thank you very much for your testimony. Counsel was just giving me the figures here. What are you asking for?

Dr. COLLER. We are trying to fund, of the grants that are approved and found worthy by the peer review system of NIH, we are hoping to support 40 percent of them.

So these are the ones that the peer review system says should be funded, are worthy of funding, and now we want to fund just 40 percent of those.

Senator HARKIN. I understand we are funding about 33 percent?

Dr. COLLER. Yes.

Senator HARKIN. Well, again, there is a lack of priorities in this country. These are things that should have a high priority, but it is going to be a battle for the funds.

I might say to you and others who are here, that the money this subcommittee has to work with right now out of the full committee, what we call our 302(b) allocations, is $100 million less than what the President requested. We have $800 million less than the House, and $900 million less than what was approved in the Senate budget yesterday.

So I can assure all of you that there are going to be some strenuous battles on the amount of money that this subcommittee has to fund these programs. And I will just say to all of you who are sitting out there that it is important for you to be here today and to testify.

It is important to make the record, to get this in the record. But I encourage all of you to do whatever else you can through your organizations, wherever possible, to get the kind of support on this full committee and in this Senate that we need to get these kinds of funds. Otherwise, we are just not going to receive them.

So I just throw that out to you. You have a lot of work to do out there to receive the support we need to get these figures changed.

Dr. COLLER. Our goal is to emphasize that not only are we dealing with the issues of health care, certainly we agree about the priority.

But because of the evolution of the biotechnology industry and unique role that American research funded by NIH has played in that, that we believe that there is an economic issue to be argued here as well on behalf of continued support.

Senator HARKIN. You are preaching to the choir, but thank you very much for your counsel. Thank you.

STATEMENT OF DR. GERARD M. TURINO, ON BEHALF OF THE AMERICAN LUNG ASSOCIATION, AND THE AMERICAN THORACIC SOCIETY

Senator HARKIN. The next is Dr. Gerard M. Turino, representing the American Lung Association. Dr. Turino, welcome to the subcommittee. Please proceed.

Dr. TURINO. Thank you. Mr. Chairman, the American Lung Association and American Thoracic Society thank you for this opportunity to comment on the health and biomedical research programs in the fiscal year 1989 budget.

I am Dr. Turino, immediate past president of the American Thoracic Society, and also for the past 3 years chairman of the Pulmonary Disease Advisory Committee of the NHLBI. Presently I am professor of medicine at Columbia University College of Physicians and Surgeons.

At the outset, Mr. Chairman, I would like to thank you for this subcommittee's continued support of biomedical research programs. This support is critical chiefly in view of the attempts by the administration to limit support for health-related research.

In my spoken comments I would like to focus on the financial support for training and career development of research scientists in diseases of the lung. Diseases of the lung constitute a devastating ongoing health problem in the United States.

Estimates for 1986 indicate that over 83 million Americans are afflicted with chronic respiratory illness. In the aggregate, lung diseases, including lung cancer, rank third among the leading causes of death.

The combined direct and indirect costs of lung disease was a staggering $44.6 billion in 1987. At the present time we are virtually in the midst of an explosion of knowledge in biomedical science, in the area of molecular and cellular biology, immunology, and genetics.

Advances in these disciplines could have a critical impact on our understanding of diseases of the lungs and respiration at a very fundamental level, which can only lead to therapies and prevention which will be more effective than ever before.

Basic to the ability of medicine and biomedical science to apply this new knowledge and technology is the development of the highest quality research scientists. Financial support for training and career development of research scientists in the area of respiratory disease, therefore, becomes a central issue.

At present, NHLBI supports 29 percent of all career awards within the National Institutes of Health. However, NIH support for training is decreasing, causing great concern within the research community.

In fiscal year 1980, 5.1 percent of NIH funds supported research training. But by fiscal year 1987, this had decreased to 3.1 percent. Within the area of lung research, the NHLBI has developed its own forms of training grants tailored to the needs of lung research, such as the clinical investigator award and the preventive pulmonary award. These and other training mechanisms must be sustained.

The President's budget provides for no new training awards and provides only a 2-percent increase in funds for existing programs. The ALA-ATS urges the subcommittee to provide additional funds for NHLBI training and career development initiatives.

An additional $2 million is necessary to permit NHLBI minimal flexibility in meeting its training objectives. A further $5 million are necessary to build upon existing programs and allow for new awards.

In conclusion, Mr. Chairman, support of the Federal Government is essential to the programs devoted to the reduction of death and disability from diseases of the lungs and respiratory tract.

We are in the midst of a broad and unprecedented advance in our ability to learn the basic causes of lung disease, as well as their treatment and prevention. We can only utilize this remarkable opportunity in the biomedical science of lung disease in which the trained scientists move forward with these advances.

PREPARED STATEMENT

Thus now more than ever vigorous support and adequate resources are essential if we are to improve the health of the Nation in this critical area of human disease. Thank you, Mr. Chairman.

Senator HARKIN. Thank you very much, Dr. Turino. You are asking for a level of funding for $1.187 million. Thank you very much. We appreciate it.

[The statement follows:]

STATEMENT OF DR. GERARD M. TURINO

Mr. Chairman and Members of the Subcommittee, the American Lung Association and the American Thoracic Society, ALA's medical section, thank you for this opportunity to comment on the health and biomedical research programs in the FY 89 budget. I am Dr. Gerard M. Turnio, Past-President of the ATS. In my professional capacity I am Director of the Medical Service, Department of Medicine, St. Luke's-Roosevelt Hospital, New York City. I have just completed a term as Chairman of the NIH Pulmonary Diseases Advisory Committee.

At the outset, Mr. Chairman, I would like to thank you for the Subcommittee's continued support of biomedical research programs. This support is ciritical in view of the attempts by the Administration to limit support for health related research.

The ALA/ATS has reviewed the lung related research, training, and demonstration programs for the National Heart, Lung and Blood Institute as well as for other institutes and agencies conducting activities related to the prevention and control of lung disease. The recommendations represent our best estimate of the adequate resources necessary to continue these programs at the level of priority funding indicated by the magnitude of the lung disease problem. The funding levels include recommendations for AIDS activity as appropriate.

SUMMARY: FY 89 HEALTH APPROPRIATIONS RECOMMENDATIONS

National Heart, Lung and Blood Institute	$1,187.0 M
National Institute of Allergy and Infectious Diseases	766.0 M
National Institute of Environmental Health Sciences	258.7 M
National Institute for Occupational Safety and Health (CDC)	84.0 M
Tuberculosis Project Grants (CDC)	31.0 M
Office on Smoking and Health (CDC)	5.0 M
Office of Health Promotion (CDC)	5.0 M

Diseases of the lung constitute a devastating and growing health problem in the U.S. In 1986, it was estimaed that over 83 million Americans had chronic respiratory disease, a categorization including seven conditions ranging in severity from chronic sinusitis to chronic bronchitis and emphysema. In the aggregate, lung diseases including lung cancer, ranked third among the leading causes of death. Chronic Obstructive Pulmonary Disease (COPD) and allied conditions are the most rapidly increasing of the top ten leading causes of death between 1970 and 1984. The age-adjusted death rate due to lung cancer and COPD increased 35% and 36% respectively. The combined direct and indirect costs of lung diseases were a staggering $44.6 billion in 1987.

Grim as this statistical picture appears, it is not hopeless. Federal programs for disease prevention and health promotion, biomedical research, environmental and occupational health hazard control, and professional education and training have greatly improved the detection and treatment of many lung diseases. Furthermore, many exciting advances place us on the threshold of new diagnostic methods.

THE NATIONAL HEART, LUNG AND BLOOD INSTITUTE

The National Institutes of Health represent the largest source of funding for lung related research in the U.S. This research program--principally within the National Heart, Lung and Blood Institute--has contributed significantly to the remarkable progress made in the past decade toward unmasking the basic biological events underlying the development of lung diseases, and devising treatments and preventive strategies for these diseases. The NHLBI research portfolio includes several research mechanisms of importance to lung related research.

o **Research Projects:** The Project Grant continues to be the keystone of the NHLBI research program. The largest portion of the research portfolio is dedicated to this mechanism. An exciting new area of research for the Institute involves investigation utilizing new technologies in molecular biology. The Institute has initiated "Programs of Excellence in Molecular Biology" to fund multidisciplinary research units designed to integrate molecular biology technologies with cardiovascular and pulmonary research. In the first competition only 3 of 19 applications received can be funded.

A major problem in the management of the Projects mechanism related to the average cost of a grant. Each year the average cost of an NHLBI grant has increased more than the estimated average cost appropriated by Congress to support the new and competing research projects. In FY 78 the cost was $89,000/grant increasing to $242,000/grant in FY 88. This increase is due in large part to the proportion of clinical research sponsored by NHLBI which has higher costs due to patient care, personnel, and equipment needs. It is also due, in part, to the annual increase in the cost of doing research, about 10%. This increase is not inflation in the strictest sense, but represents the development of evermore sophisticated and expensive research technologies.

A "downward negotiation" is required to offset this difference. The President's budget proposal would reguire a 11.4% reduction from the recommended level for noncompeting grants and a 13.5% reduction from competing grants. The difference between the estimated average cost and the actual cost has significant impact on the integrity of the research program. For the individual investigator, the ability to accomplish all the objectives set out in the grant becomes more difficult, and in some cases, this reduction may make completion of the grant impossible. For a large program project grant, such a reduction can cause the dismantling of a research team. An additional $22 million for this mechanism is necessary to restore funds to acceptable levels.

o **Research Centers:** The NHLBI supports 63 Specialized Centers of Research--SCORs. The SCOR program is a unique research mechansim that emphasizes both basic and clinical research to ensure that advances in the basic sciences are quickly translated into applications at the clinical level. This research mechanism directly benefits patient and public health.

Several SCOR programs are managed by the Division of Lung Diseases (DLD). SCORs include programs in Chronic Diseases of the Airways, Pediatric Pulmonary Diseases, Occupational and Immunologic Lung Diseases and Pulmonary Vascular Diseases. NHLBI will initiate a modest increase in the Centers program within DLD with FY 88 funds. New programs are anticipated in Cardiopulmonary Disorders of Sleep and Cystic Fibrosis (jointly funded with NIDDK).

The President's budget proposal provides for no increase in funds for the Centers program. New activity may therefore jeopardize existing activity. An additional $5 million is necessary for the Centers mechanism to provide minimun flexibility in planning.

o **Research Contracts:** The NHLBI supports a number of Clinical Trials through the Contracts mechanism. In the DLD, a major trial--The Lung Health Study--has been initiated to study COPD. This trial represents an 8-year obligation by the

Institute to determine if those individuals considered at risk for the development of COPD can avoid it through a series of intervention strategies including the use of certain bronchodilator medications. The outcome of this trial is of primary interest to the pulmonary community. Successful completion will require significant resources over the period of the trial. A major portion of resource utilization is occurring at the present time in activity related to equipment acquisition, and patient recruitment, assessment, treatment and surveillance. An additional $5 million is necessary to continue this and other ciritical activity underway as well as initiate new priority studies.

- **Continuing Progam Issues:** A continuing problem for the NHLBI is the growing imbalance in the research program. The distribution of funds among the research mechanisms has markedly changed in recent years impacting the ability of the Institute to maintain a balanced program. The percentage increase of funds to Research Projects has been made at the expense of other research mechanisms. Projects received 50.6% of the total Institute funds in 1980, growing to 63.4% in 1987. However, Centers and Contracts have declined--Centers were funded at 11.8% in 1980, declining to 9.7% in 1987 and Contracts were funded at 15% in 1980, declining to 6.7% in 1987. While the funding of research projects is an important component of the NHLBI program, support for other research mechanisms must be maintained to achieve program balance.

A final issue with direct impact on the NHLBI research program is the lack of flexibility in program management. Congress should continue to require OMB to apportion funds appropriated to the NIH at the individual institute appropriated level. Such action can restore flexibility to program management and allow institute directors to take timely advantage of new and emerging research opportunities.

THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

The research responsibilites of the National Institute of Allergy and Infectious Diseases include a number of respiratory disorders including allergic asthma and infectious diseases such as influenza and pneumonia. Also of concern are other bacterial, viral, and immunologic diseases that affect the lung. It was support from NIAID which led to a vaccine against pneumococcal pneumonia.

A major interest to ALA/ATS is NIAID research support directed to decreasing Tuberculosis morbidity and mortality. The magnitude of the TB problem in the U.S. has decreased significantly in part due to the introduction of chemotherapy. However, TB remains a serious public health problem affecting primarily minorities and the socioeconomically disadvantaged. The incidence of TB was steadily declining in the U.S. until 1986 when an increase was observed. One of the factors identified for the increase is the occurrence of TB in persons with HIV infection or AIDS.

In recent years new developments in basic sciences have led to improvements in the prevention, diagnosis and treatment of many infectious diseases. However, these improvements have not been applied or studied in relation to TB. In 1985, the NIH, CDC, Pittsfield Antituberculosis Association, and ALA/ATS cosponsored a conference to identify priority areas of research. As a result of this conference, NIAID has begun a new initiative in TB. Areas of proposed study have the promise of leading to a DNA probe for rapid detection of infection, development of new drugs and drug delivery systems, new preventive therapy regimens, and a new vaccine. The ultimate eradication of TB from the world may depend upon the development of a "simple" intervention such as a reliably effective vaccine.

The Congress reauthorized the TB Project Grants in 1988 and included an important new component--authority to the Secretary of HHS to use a research set-aside. ALA/ATS urges the Subcommittee to fund the TB Project Grants at the full authorized level of $31 million and recommends use of the set-aside funds to intensify NIAID research activity related to TB.

THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES

The respiratory system is the organ system bearing the heaviest burden of environmental contamination. The National Institute of Environmental Health Sciences devotes a significant portion of its research and testing resources--approximately 20%--to the study of the lung, both as a major route of exposure and as a frequent target of damage by environmental agents. As is the case in NHLBI, the distribution of funds to the NIEHS also favors Research Project Grants at the expense of other mechanisms of support including Centers and Contracts.

o **Research Centers:** The NIEHS supports 16 Environmental Health Science Centers. One of the critical activities conducted in these centers is research on the health effects of air pollution and acid rain. The so-called "Six Cities Study" is in its 14th year and is a major component of the Harvard Environmental Health Science Center. This is a study of health effects of air pollution from fossil fuels involving 2000 children in six cities. Findings from this and other such NIEHS supported activities have provided a large share of the data used by EPA to set health based standards under the Clean Air Act. The President's budget proposal provides no new funds for this important research mechanism. At least $5 million in additional funds is necessary to continue activity underway as well as initiate new projects.

o **Research Contracts:** The NIEHS administers the National Toxicology Program established in 1978 to increase knowledge about the toxicology of chemicals including the evaluation of toxic health effects. This program is managed through the contract mechanism. A significant portion of activity relates to substances administered by inhalation. For example, a series of studies are on-going to evaluate the toxicity of chemicals found in the semiconductor industry. Data of this sort is not only useful to NIOSH in evalutating workplace health concerns but also to EPA in evaluating toxic air pollutants for listing under the Clean Air Act. The President's budget proposal provides no new funds for this area of activity. At least $13 million in additional funds is necessary to provide for growth in this important program.

In conclusion, Mr. Chairman, the federal government provides a significant source of funding to a wide range of programs directly impacting the prevention and control of lung disease. In the absence of adequate federal support, neither the state nor local governments, nor the private sector are financially capable of assuming this level of programming. The health and biomedical research programs of the federal government give strength and leadership to our entire health care system. We are now looking at opportunities in biomedical research that will lead to significant improvement in the health of the nation. Thus, now more than ever, vigorous support and adequate resources are essential.

STATEMENT OF DR. MARVIN I. DUNN, PRESIDENT-ELECT, AMERICAN COLLEGE OF CHEST PHYSICIANS, AND FRANKLIN E. MURPHY PROFESSOR OF MEDICINE AND DIRECTOR OF CARDIOVASCULAR LABORATORIES AT THE UNIVERSITY OF KANSAS MEDICAL CENTER

Senator HARKIN. Next is Dr. Marvin Dunn, president-elect of the American College of Chest Physicians, and Dr. Franklin Murphy, University of Kansas Medical Center.

Dr. DUNN. No; that is my professorial title. I am here all alone.

Senator HARKIN. Oh, I see. You are Dr. Marvin Dunn?

Dr. DUNN. That is correct.

Senator HARKIN. You must occupy the Dr. Franklin E. Murphy chair at the University of Kansas Medical Center. They left the word "chair" out of here.

Dr. DUNN. That is right.

Senator HARKIN. Thank you, Dr. Dunn, for being here, and please proceed.

Dr. DUNN. Senator Harkin, I am Dr. Marvin Dunn, president-elect of the American College of Chest Physicians. I am also the Franklin E. Murphy professor of medicine and director of the Cardiovascular Laboratories at the University of Kansas Medical Center in Kansas City, KS.

I would like to thank you for the opportunity to testify on behalf of the American College of Chest Physicians. The college is a professional medical specialty society of more than 13,000 physicians, scientists, and educators who specialize in disease of the heart, lung, and circulatory system. It is one of the major organizations representing critical care medical physicians.

The college appreciates this opportunity to speak in support of the 1989 appropriation for the National Heart, Lung and Blood Institute on the pulmonary activities of the National Institute of Allergy and Infectious Disease.

Recognizing the strains that have been placed on the Federal budget, we are nevertheless committed to maintaining the tremendous strides that have been made in combating the ravages of cardiac and pulmonary disease.

We are proud of the achievements of the National Heart, Lung and Blood Institute under the leadership of Dr. Claude Lenfant. Realizing that heart and lung disease accounts for over 60 percent of the deaths in the United States annually, and realizing that one-third of these deaths occur in people under age 65, we consider this to be a problem of major importance.

We recognize that deaths from these disorders have declined in the past decade. This is in part due to significant diagnostic and therapeutic achievements, many of which were funded through the National Institutes of Health.

Through the three decades of my professional career, the NIH has provided leadership in cardiovascular research, education, and patient care. It has provided funds for postgraduate training and research training for most of the leaders in the cardiovascular field today.

Dr. Weisfeldt has already commented on certain programs of the NIH and the National Heart, Lung and Blood Institute that we also support. For these reasons, and to continue the progress that has been achieved to date, we wish to express our support for an appropriation level of $1.187 billion for the National Heart, Lung and Blood Institute, and for $8.471 billion for the total NIH budget for fiscal year 1989.

PREPARED STATEMENT

This level would be consistent with the commitment of our organization to support biomedical research, and our major goal and commitment, which is to improve the health of the citizens of our Nation.

Senator HARKIN. Thank you very much, Dr. Dunn, for your testimony and for being here this morning.

[The statement follows:]

STATEMENT OF DR. MARVIN I. DUNN

I am Dr. Marvin I. Dunn, President-Elect of the American College of Chest Physicians. I am also the Franklin E. Murphy Professor of Medicine and the Director of Cardiovascular Laboratories at the University of Kansas Medical Center in Kansas City, Kansas.

I would like to begin by thanking you for affording me the opportunity to testify on behalf of the American College of Chest Physicians. ACCP is a professional medical specialty society of more than 13,000 physicians, scientists and educators who specialize in diseases of the heart, lungs and circulatory system. The College appreciates this opportunity to offer our views to this Committee on fiscal year 1989 appropriations for the National Heart, Lung and Blood Institute (NHLBI), and the pulmonary activities of the National Institute of Allergy and Infectious Diseases (NIAID).

I would like to preface this statement by emphasizing that ACCP enthusiastically supports the activities of the National Institutes of Health, particularly those of NHLBI and NIAID. We unequivocally support NIH's commitment to support the entire spectrum of research, both basic and applied; both for treatment and prevention. The investment in these areas over the past year has been extremely productive.

With regard to NHLBI, under the very able leadership of Dr. Claude Lenfant, tremendous strides continue to be made in combatting cardiovascular and cardiopulmonary diseases. ACCP's recommendations are aimed at maintaining that momentum. Although we recognize the strains that have been placed on the federal budget in recent years, the fact that diseases of the heart and lungs continue to pose the most serious threat to our Nation's health must not escape us. The desirability of exercising fiscal austerity should not cause us to lose sight of this fact.

According to NIH, cardiovascular diseases afflict more than 70 million people. In 1986, 979,000 deaths or roughly fifty percent of all deaths were attributed to cardiovascular diseases. The prevelence of arteriosclerotic-related cases is reflected in an examination of the deaths by diagnosis: coronary heart disease, 524,000 deaths; stroke, 148,000 deaths; and peripheral vascular disease, 44,000 deaths. Other cardiovascular diseases such as hypertension led to 263,000 additional deaths. Some 73 million persons have been diagnosed as having hypertension, or heart/circulatory disease. In 1985, 21 million persons had some form of heart disease; 6.7 million with coronary heart disease, 1.5 million with rheumatic heart disease, 12 million with other forms of heart and vascular disease. More than 2.7 million persons were estimated to have cerebrovascular disease.

In addition to the untold costs of human suffering, cardiovascular diseases are responsible for a loss of well over one hundred billion dollars each year in productivity, wages and costs of medical care. The most telling statistic, however, is that cardiovascular diseases continue to be the number one cause of death in this country. Indeed, if one adds lung and blood diseases to the tally, the stark reality is that 1,159,000 deaths in 1986 or over fifty-five percent of all deaths fall within the disease categories that it is the mission of NHLBI to combat. These diseases represent five of the ten leading causes of death. And yet despite this fact, NHLBI's allocation among the NIH institutes amounts only to approximately 15%.

Two points need particular emphasis. First, while the efforts of NHLBI have helped lead to a significant decline in the death rate from cardiovascular diseases over the past twenty years, the incidence of these diseases and their costs, in terms of human suffering, death, economic loss remains staggering. Second, when one views the progress made to date and takes into account the costs that would have been incurred had it not been for the work of NHLBI, the conclusion is clear: monies spent to combat these diseases have been monies well spent. Indeed, I believe it fair to say that for every dollar spent by NHLBI, the return in terms of dollars not spent on health care, etc. exceeds most other expenditures by the federal government.

It is therefore imperative that NHLBI be afforded sufficient resources to continue its efforts to combat the full panoply of cardiovascular diseases: hypertension, cereberal vascular disease, coronary heart disease, arrhythmias, heart failure and shock, congenital and rheumatic heart diseases, cardiomypathies and heart and circulatory system-infection. Although the NHLBI has made considerable progress in the cardiovascular area, the battle against these diseases is far from over.

It is therefore vital that research efforts be supported so that new information can be obtained that will lead to further insights about cardiovascular diseases. For example, NHLBI supported investigations have elucidated the mechanisms involved in the regulation of levels of blood lipids by receptors on the surface of the liver and other cells that produce particles of low density lipoproteins (LDL) and remove these from the blood stream. The LDL is taken into the cells where it is broken down and yields its cholesterol to serve the cell's needs.

When the receptors are defective, LDL cannot be removed normally, and it accumulates to high levels in the blood plasma. The build-up accelerates the atherosclerotic process. Mutations in one of the genes for the receptors can produce heterozygous familial hypercholesterolemia, which is a cause of heart attacks in middle-aged people. Persons who inherit one of these mutant genes for the LDL receptor usually develop heart attacks.

Genetically induced alterations in the LDL receptor have now become the subject of intensive research. Recently, it has become possible to study the molecular genetics of these mutations as a result of the cloning of complementary DND (cDNA) for the human LDL receptor and the subsequent isolation of genomic clones covering most of the LDL receptor gene. This information would be used to develop insights into the management of the inherited disease, familial hypercholesterolemia, and methods to intervene and control high blood cholesteral.

NHLBI has provided effective leadership in this battle against cardiovascular diseases. Research supported by NHLBI has contributed to such achievements as open heart surgery, cardiac transplants, cardiovascular and respiratory intensive-care units, diagnostic instruments for use in lung disease, and the virtual elimination of hepatitis B as a transfusion hazard. NHLBI has also contributed greatly toward assuring the safety of the Nation's blood supply by supporting the development of tests to detect the presence of HIV or its antibodies in donated blood. ACCP applauds these achievements. Furthermore, the College supports NHLBI's ongoing basic research efforts involving such areas as: the relationship between behavior and coronary heart disease, the relationship between diet and artherosclerosis, and the use of immunosuppressive therapy to facilitate heart-lung transplants, to name a few.

Several new programs being implemented by NHLBI are particulary worthy of support and hold great promise in increasing our understanding about and ability to prevent and treat diseases. The Programs of Excellence in Molecular Biology will combine molecular biology research with basic research in the heart, lung and blood areas. The newly created Laboratory of Cardiac Energetics, utilizing a state-of-the-art imaging device, promises to lead to new knowledge about the metabolic aspects of the human heart. The College recommends that the Committee provide the necessary funding to support these new and exciting programs. Funding should be increased as well to support the Institute's Education Programs, specifically, the National High Blood Pressure Education Program, the National Cholesterol Education Program, the Smoking Education Program, and the new National Blood Resources Education Program.

NHLBI's concerns are far broader than cardiovascular diseases. NHLBI has also achieved an excellent strategy

In order to meet its mandate, the NHLBI needs to utilize a number of mechanisms to support research. For instance, most investigator initiated research projects support basic research and small scale clinical studies. Research centers are used to support multidisciplinary research focused on major disease entities and to assure that the fundamental research outcomes are rapidly made available to the clinical arena. Research and Development contracts are the best mechanism to support clinical trials and other population-based studies.

Time does not permit me to discuss the nature of these Clinical Trials in detail. These clinical trials are designed to test, in a carefully controlled setting, the efficiency and safety of preventive and therapeutic regimens before these regimens are introduced into practice. The results of clinical trials are critical. They ensure that unwarranted hospitalizations and premature surgery is avoided, thus helping reduce the costs of health care for our nation. Over the entire century, the gains achieved through expansion in medical research have always far exceeded the level of federal investment.

Given the demonstrated economic soundness of biomedical research activities, increased appropriation levels for NIH, and particularly NHLBI, should be a national priority. An increase, at a minimum sufficient to counteract the rate of inflation and avoid downward negotiations in the amount available for biomedical research grants, should be sought. The ACCP believes that in order for NHLBI to be able to continue to fulfill its mandate and provide the leadership which is crucial to our national biomedical research effort, an appropriation of $1.187 billion is necessary for fiscal year 1989.

The National Institute of Allergy and Infectious Diseases, NIAID, sponsors important research projects which have broad implications in the respiratory field. Studies involving influenza viruses, and respiratory syncytial and parainfluenza viruses, provide important additions to our current level of knowledge of degenerative chronic diseases. Because of the importance of NIAID's research efforts related to viruses, and its study of such diseases as pneumonia and menigitis, ACCP strongly supports increased funding, to a level of $766.6 million, for NIAID.

In sum, the College wishes to express its support for an appropriation level of $8.471 billion for fiscal year 1989 for the National Institutes of Health (NIH). This recommended level of funding would be consistent with our national commitment to biomedical research and would translate into an appropriate, sound, and progressive level of NIH research activity which accurately reflects its vital mandate.

Today, the ACCP continues to lend its support to those research efforts which are aimed at the ultimate approach to cost-saving -- prevention. NIH appropriation levels must be increased to insure that our progress toward that goal is not thwarted. The Federal Government must not turn its back on biomedical advances of the future which could yield billions of dollars in health care savings. Funding levels consistent with the important goals and essential mandate of NIH must be achieved. On behalf of ACCP's membership, I would like to thank you for affording us this opportunity to present our views.

STATEMENT OF DR. LEON W. HOYER, ASSOCIATE VICE PRESIDENT OF BIOMEDICAL RESEARCH AND DEVELOPMENT, AMERICAN RED CROSS, ON BEHALF OF THE NATIONAL HEMOPHILIA FOUNDATION

Senator HARKIN. Next is Dr. Leon Hoyer, the National Hemophilia Foundation. Dr. Hoyer, welcome to the subcommittee. Please proceed.

Dr. HOYER. Senator Harkin, I am Dr. Leon W. Hoyer. I am associate vice president for Biomedical Research and Development for the American Red Cross Blood Services. I am speaking to you today as a representative of the National Hemophilia Foundation. Thank you for this opportunity.

The written testimony discusses the specific funding issues that are vital to the 20,000 patients with hemophilia in the United States, and for their families. I would like to emphasize in these few minutes a typical problem that I faced as a clinician, and that is faced by the patients with hemophilia.

I will simply present a dilemma. That of a young man with severe hemophilia I first saw at the University of Connecticut in 1975 when he was 14 years old. Because of the newly available factorate concentrates and a great deal of support and attention from relatives, he had not developed severe joint disease.

He learned to administer the factorate to himself at home or at school. Soon he was in college, then in an outstanding physics graduate program, and finally he spent 1 year overseas on special fellowship. He has earned his doctorate.

That is quite a story for a young person with hemophilia, a boy whose bleeding disorder could have led him to a wheelchair only 5 years ago. But 5 years ago many things changed.

All of us became aware that hemophiliacs were developing AIDS. It is now known that over 90 percent of patients with severe hemophilia have been exposed to the AIDS virus. The virus had been present in the coagulation factor concentrates that have been so important for these patients.

What is the future for this man? No one knows for sure. Though it is a tragic fact that throughout this country, 4 percent, 1 in every 25, patients with severe hemophilia have died of AIDS.

We know that unless risk reduction measures are taken, these men will transmit the virus to their wives, and their pregnancies will have a significant possibility of transmitting AIDS to their offspring.

What needs to be done? The National Hemophilia Foundation urges the subcommittee to support and to champion three urgently needed appropriations. The first is increased support for the Hemophilia Treatment Center Program and retention of the 15-percent set-aside within the maternal and child health appropriation.

Second, a special appropriation to the Centers for Disease Control and to the Office of Maternal and Child Health to expand the risk reduction, education, and training programs.

Bill report language supporting these two recommendations has been submitted to you, and the combined total will require less than $1.8 million. In addition, increased support to the NIH is essential, so that it continue and expand research directed toward the development of nontoxic drugs that can be used to eliminate the AIDS virus from infected individuals.

In conclusion I want to emphasize how much everyone concerned with hemophilia appreciates the support this subcommittee has provided for hemophilia research and treatment during the past 12 years.

PREPARED STATEMENT

Because we are now faced with an even more difficult problem due to AIDS, we are asking you to find even more support for comprehensive care, research, and effective management of these unique problems. Thank you very much.

[The statement follows:]

STATEMENT OF DR. LEON W. HOYER

I am Leon W. Hoyer, MD. I am Associate Vice President of Biomedical Research and elopment for the American Red Cross and I am speaking to you today as a representative of The National Hemophilia Foundation (NHF). I am a member of the research review committee of NHF's Medical and Scientific Advisory Council.

In 1975, Congress passed legislation creating a revolutionary federally funded comprehensive diagnosis and treatment center program for people with hemophilia. In 1976, the first year of federal support for this program provided funding for the development of 24 comprehensive Hemophilia Treatment Centers and 60 affiliates on a regional basis. About 10,000 persons with hemophilia (50% of the total hemophilia population) are now served by these centers, which provide multi-disciplinary services including psychosocial, financial and vocational counseling, in addition to medical, dental and orthopedic care.

While this program has been of substantial benefit to the hemophilia community, I regret to report to you that the staggering impact of AIDS is seriously undermining the progress we have made over the past decade. It is not "business as usual" with hemophilia treatment and research. One in every 30 individuals with hemophilia has contracted AIDS and, for those with severe hemophilia, the rate is one in 26. When we last testified before this committee, the rate was one in every 67. In addition,90% of persons with severe hemophilia have developed antibodies to HIV.

PROGRESS IN REDUCING THE RISK OF AIDS AMONG PEOPLE WITH HEMOPHILIA - As a result of enormous collaborative efforts between the public and private sectors, there has been stantial progress in reducing the risk of AIDS among patients and families affected by hemophilia. Because blood donations are tested and blood products used by people with hemophilia now utilize a variety of viral inactivation processes, such blood products are now virtually free of HIV contamination.

Thanks to your support, a number of additional initiatives have been set in motion, lizing the regional building blocks and framework you established in 1976. These projects represent a cooperative effort between the public and private sectors involving numerous federal agencies and treatment centers throughout the United States and The National Hemophilia Foundation. A report on the considerable progress made through these efforts will be sent to you within the next few weeks.

Concern remains, however, about the potential that the large percentage of antibody positive people with hemophilia have for transmitting HIV to their sexual partners. It is vital that people with hemophilia maintain their treatment of bleeding episodes when medically indicated, despite their fear of AIDS. Special attention is also needed to address AIDS-related stress among patients and families. But, most important of all, concern persists over how many of the 90% of people with severe hemophilia who are HIV-antibody positive will succumb to AIDS.

APPROPRIATIONS REQUEST - The issues that I have addressed can be translated into the following requests for appropriations:

1. FY89 Appropriations for Hemophilia Treatment Centers - We urge you to appropriate $4.9 million for FY89 to support the treatment centers program. This $1.4 million increase is essential to expand the existing regional network to areas and patients not currently served (about 50% of the total). The modest amount of seed money needed to stimulate the development of comprehensive care can yield substantial returns in a very short period of time, as demonstrated in Georgia, where comprehensive care erwent remarkable development and expansion in just two years.

We also request that you retain the 15% for a set-aside within the MCH appropriations, because it is more efficient to distribute resources for certain disorders on a regional and national basis than through block grants to the states. We also urge that MCH, of which the hemophilia program is a part, be funded at the full horization level.

About one in 56 children affected by hemophilia has developed AIDS and many more are HIV positive. In view of this, we wish to thank you for providing pediatric-related AIDS funding support last year through HRSA. We hope that some of the pediatric AIDS funding support will be used to address the tragic situation of children barred from their classrooms due to the public misunderstanding and fears about how AIDS is, and is not, spread. This is but one of many areas needing support for the benefit of children with hemophilia and the many other children affected by AIDS. We urge a substantial increase in pediatric AIDS funding.

2. EMERGENCY APPROPRIATIONS FOR RISK REDUCTION, EDUCATION AND TRAINING - Now that the blood supply is no longer considered a source of HIV transmission to the hemophilia community, the major concern is the potential risks associated with sexual and perinatal HIV transmission. The hemophilia community represents a model for heterosexual transmission, as its population is amenable to surveillance and is relatively self-contained and stable, with the highly regionalized services concentrated in the federally supported treatment centers. To effectively reduce the risk of heterosexual transmission of HIV, health education and behavioral changes in the hemophilia community must be well understood and documented. These efforts will be of benefit to all in combating AIDS.

We are most grateful for your support in providing funding to assist us in addressing these risk reduction, psychosocial, education and training needs. Preliminary a from 72 treatment centers indicate that our efforts have already achieved some notable successes. Yet, substantial and sometimes overwhelming problems remain. Studies have documented that, despite educational efforts, many couples elect not to follow safer sexual practices. As a result, 10-20% of partners are now antibody positive and the numbers are growing. Also, as cited earlier, the number of AIDS cases in the hemophilia ›ulation has more than doubled in just one year. We request an additional $1 million over the $6.3 million provided through CDC and OMCH for the upcoming year.

3. RESEARCH - Thanks to your support and to that of the Director of NIAID, May 2, 1988, marked the beginning of a nationwide study, conducted by ten federal treatment centers and their affiliated medical centers, to evaluate the safety and efficacy of AZT and determine if it can prevent or slow progression to AIDS in HIV infected hemophilia patients with no symptoms of AIDS. This clinical research network represents an innovative AIDS treatment and evaluation model that may be further utilized as new therapies for AIDS become available. Also, this study will benefit the larger community by providing valuable research data. It is most important to substantially increase the funding to support the vitally important work of NIAID.

The AIDS tragedy painfully reminds us that, as long as people with hemophilia depend upon a factor derived from human blood plasma, they will be vulnerable to anything that may contaminate blood products. In addition, clotting factor inhibitors develop in over 10% of people with hemophilia and these antibodies seriously compromise subsequent care. Also, people with hemophilia still suffer from extremely painful joint damage as a result of frequent bleeding episodes. There must be adequate funding for basic biomedical research provided by the NIH and especially the blood diseases and resources research program of NHLBI and the important research conducted by NIDDK and NIAMS.

The Centers for Disease Control need increased funding to expand their excellent ›oratory investigations and epidemiologic studies. The CDC Division of Host Factors has played a major leadership role in tracking the transmission of AIDS in the hemophilia community. Its longitudinal studies of AIDS and hemophilia have been of enormous value in helping us to understand the health status of persons with hemophilia and the natural history of HIV progression.

The Food and Drug Administration also needs adequate support to expand its surveillance of the safety of blood products. This support is also needed to enable FDA to expeditiously review new methods of viral inactivation so that people with hemophilia may benefit from safer blood products as soon as possible.

Preliminary data appear to indicate that blood products produced through newer processes offer the potential of improved viral safety, not only for AIDS but for hepatitis viruses. Unfortunately, some of these products are enormously expensive (as much as 800% more than the price of conventional, dry-heated product) and they require much more plasma to produce the same amount of clotting factor. As a result, individuals and families may have their personal resources drained and the 25 state programs that subsidize the cost of clotting factor will surely run out of funds unless there are major budget supplements. Also, it appears that we are heading into a major supply crisis that could have severe health consequences if there is not enough to go around to treat bleeding episodes adequately.

SUMMARY - Over the last 12 years, we have been most pleased with the support you have provided for hemophilia treatment and research, but, today, we are faced with very serious and difficult problems as a result of AIDS. Therefore, we are asking you to help us find more support for comprehensive care, research and addressing the unique problems faced by the hemophilia community as a result of AIDS. Thank you.

Senator HARKIN. Dr. Hoyer, thank you. You are asking for $4.9 million to support the treatment centers program, a $1.4 million increase.

Dr. HOYER. That is over present funding. Actually, it is only $800,000 over the President's recommendation.

Senator HARKIN. Thank you very much.

STATEMENT OF DR. WILLIAM C. DEMENT, CHAIRMAN OF THE BOARD, ASSOCIATION OF PROFESSIONAL SLEEP SOCIETIES

Senator HARKIN. Dr. William Demend, representing the Association of Professional Sleep Societies. Dr. Dement, welcome to the subcommittee, and please proceed.

Dr. DEMENT. Mr. Chairman, thanks for the opportunity to be here. I am also aware of your work with the handicapped and appreciate it very much.

Senator HARKIN. Thank you.

Dr. DEMENT. I represent the Association of Professional Sleep Societies which has now 2,000 members.

This is a unique new clinical practice discipline that virtually did not exist 10 years ago and is based upon understanding the mechanisms and pathologies of the active sleeping brain as it attempts to regulate the vital processes of breathing, heart rate, blood pressure, and do the vital work without which we cannot function or stay alive.

You have my transcribed remarks. I would like to just make a couple of very important points. The first is that numbers do not actually give you an idea of the growth of the field.

This is the growth of the sleep centers in the United States that is exponential today. And I think it represents a public awareness of sleep disorders and that there is effective diagnosis and treatment.

We now have pulled back the curtain of the night and we are aware of the big numbers of problems. I would just like to make this point.

The National Heart, Lung and Blood Institute accepts a 4-percent prevalence rate for sleep apnea, that is 10 million. Some 20 million people have periodic leg movements during sleep; 50 million have chronic insomnia because of ignorance, illnesses, and inappropriate schedules; 100 million do not get adequate sleep; and 30 million are dangerously sleepy.

So there is danger on the highway and in hazardous occupations, nuclear powerplants, and so on. So because of the gigantic size, because there are now experts in the field, we applaud the continuing interest of this committee.

In 1986 you asked for a report from NIH, which you received in 1987. You mandated a trans-NIH committee. In 1988, you mandated and supported a center of specialized research in cardiopulmonary sleep disorders.

And now we think, we hope that we can somehow harness the expertise in the field in some focused way to develop a long-term plan, either to a commission or a special advisory board, and we would certainly recommend a study of the epidemiology of sleep disorders in America to know the extent of the problem.

PREPARED STATEMENT

We would ask for the specialized centers of research on the sleeping brain and its mechanisms. We would ask for education and training in America, and primarily we need to bring all of the excellent efforts in some sort of focused way to bear on this gigantic problem. Thank you very much.

Senator HARKIN. Thank you very much for your good testimony. We appreciate your being here.

[The statement follows:]

STATEMENT OF DR. WILLIAM C. DEMENT

Mr. Chairman and members of the Subcommittee, I am very pleased to appear before you today to discuss issues related to sleep and fatigue, and sleep disorders research.

I am here on behalf of the Association of Professional Sleep Societies which is comprised of the Sleep Research Society, the Clinical Sleep Society, the American Sleep Disorders Association, and the Association of Polysomnographic Technicians. Today, over 2,000 of my colleagues are clinically practicing, or conducting research on sleep, fatigue related catastrophes, or sleep disorders. Now more than ever before, the quality of sleep and its relationship to our waking life is being considered as a significant factor in health and safety.

Sleep disorders, and sleep related phenomenon are a part of the total health picture. Some who occasionally experience sleeplessness over a period of a night or two cannot relate to the individual who experiences nightly sleep apnea episodes, leaving him to wake up literally hundreds of times a night gasping for breath with accompanying cardiopulmonary distress. Or that of the narcoleptic patient who, even against his/her will, falls asleep while eating dinner, or talking, or driving on the freeway at 55 mph. Other sleep disorders include nocturnal myoclonus, an uncontrollable jerking of the legs that disrupts sleep. More familiar to many are insomnia, nightmares, and night terrors. Most often, individuals with chronic sleep disorders need medical diagnosis and treatment. The field has been most successful in treating sleep related problems that cause excessive somnolence during the day, such as sleep apnea and narcolepsy. You probably are aware that most major cities around the U.S. have an accredited Sleep Disorders Center, usually affiliated with a major medical center. We estimate that 30,000 to 40,000 individuals around the country seek medical diagnosis and treatment for the disorders I have just mentioned.

There is a multitude of things we do not know about sleep, and treatment of sleep related disorders. For instance, some may believe the sleeping brain is inactive, or resting. Quite the opposite is true. Though we experience sleep as a "time out", this is misleading. The sleeping brain is just as active as the waking brain, and is often more active. As well, the sleeping brain performs completely different functions than the waking brain. A patient with heart disease or lung disease may appear stable and well-managed during wakefullness, yet have hundreds of life-threatening problems during sleep. We must understand sleep's functions before we can fully move on to improve the quality of life of those who suffer sleep disorders. We hope we can investigate these factors to better understand illnesses of the sleeping brain, such as sudden infant death syndrome, narcolepsy, stroke, and other sleep associated problems such as heart attack and epilepsy, and how drugs and alcohol impair sleep.

The Trans-NIH Sleep Research Coordinating Committee, established through recommendations made by your Subcommittee has become a very valuable mechanism for the various NIH Institutes to convene and coordinate sleep research. Last fall, under the chairmanship of Dr. F.J. Brinley of the National Institute of Neurological and Communicative Disorders and Stroke, the Trans-NIH Committee held a public meeting of representatives from various institutes, federal agencies, NIH Advisory Councils, the sleep research field, and voluntary organizations concerned with sleep. All of the participants stressed the importance of adequate peer review for sleep related research applications. There is a consensus that peer review committees frequently have inadequate sleep research expertise.

Suggestions for remedying this problem include the creation of a newly chartered study section to review sleep research applications, the use of special Ad Hoc Study Sections, and the appointment of sleep researchers to presently chartered review committees. The Association of Professional Sleep Societies supports each of these recommendations. As well, we believe it would be very helpful to the Trans-NIH Sleep Research Committee if a number of sleep experts were appointed to serve on the Coordinating Committee in an advisory capacity.

At the prompting of your Subcommittee, Mr. Chairman, the National Heart, Lung and Blood Institute has initiated development of a program of Specialized Centers of Research (SCOR) in Cardiopulmonary Disorders of Sleep. Cardiopulmonary disorders during sleep, and particularly sleep apnea syndrome, are among the more common of these disturbances. It is known now that this syndrome is not at all rare in the general population, especially among those who are obese or hypertensive. NHLBI is developing the SCOR programs to address such topics as neural control of respiration during sleep, the neurochemical modulation of cardio-respiratory rhythms, the control of cardiovascular function during sleep, and the epidemiology of sleep apnea. Mr. Chairman, this is one of the most significant developments ever in sleep research history, and we appreciate the support your Subcommittee has demonstrated for this initiative.

As mentioned earlier, there is a significant knowledge gap in the basic mechanisms of sleep, and that of the sleeping brain. Experts in the field believe there is a great wealth of knowledge that can be gained by carefully focusing research activity in these two closely related areas. Because of Federal interest in sleep and public policy, it is no longer humorous or fashionable to snicker at a colleague sleeping at a meeting or a congressional hearing. Sleeping at the wrong time causes untold carnage on our highways and in our industries. Imagine the benefits to society if everyone got a good nights sleep every night, or if we could eliminate the drowsy, inattentive nuclear power plant operator (the accidents at Cheyrnoble, Three Mile Island, and numerous others occurred at times when the body is greatly predisposed to sleep). Perhaps we could better understand other challenges, such as Sudden Infant Death Syndrome. Our Association urges that a greater focus be placed upon this important area of research that has yet to be fully pursued. The development of specific mechanisms within NIH is encouraged to facilitate this initiative.

Finally, Mr. Chairman, because in recent years there has been an increased focus on basic sleep research, and the sleeping brain, we have begun to assimilate a growing degree of epidemiological information and data that is useful to the research and clinical sleep disorders community. In our view, to preserve and have this information readily at hand, we recommend that a sleep information and epidemiology data program be developed through the NIH or NIMH. This is very critical to the continued development of our field.

Mr. Chairman, the biomedical research community, and those millions of Americans who benefit from scientific and medical advances are appreciative of the unyielding support and wisdom that you and your Subcommittee provides each year during consideration of funding for the nation's health programs. We do not take this for granted, Mr. Chairman.

The Association of Professional Sleep Societies supports the overall NIH recommendation of $8.5 billion for FY'89, consistent with that of the Ad Hoc Group for Medical Research Funding. I am very pleased to respond to any questions you have.

STATEMENT OF PRISCILLA CICCARIELLO, CHAIR, NATIONAL MARFAN FOUNDATION

Senator HARKIN. Next is Priscilla Ciccariello, chairperson of the National Marfan Foundation. Welcome to the subcommittee, and please proceed. Do we have a copy of your testimony?

Ms. CICCARIELLO. I sent one in.

Senator HARKIN. Oh yes, here it is.

Ms. CICCARIELLO. I am glad that you do. Senator Harkin, members of the committee, I thank you for the opportunity to speak before you today.

I am Priscilla Ciccariello, the chair of the National Marfan Foundation. The National Marfan Foundation is a nonprofit voluntary agency working on behalf of persons and their families affected by the Marfan syndrome, the genetic disorder that needlessly took the life of Olympic volleyball star Flo Hyman, Maryland basketball player Chris Patton, my son and husband, and thousands more.

Marfan syndrome is a potentially fatal genetic disorder of the connective tissue characterized by tall stature, long limbs and fingers, scoliosis, cardiac complications, and subluxation of the lenses of the eyes.

It is estimated that up to 40,000 people in the United States have this condition, but for a number of reasons many do not know they have it. President Lincoln, Paganini, and Rachmananoff are among those suspected to have had the Marfan syndrome.

In our concern for this life-threatening and disabling disorder, we support the funding currently allocated for the National Institutes of Health because this helps to address the specific concerns of the foundation.

The lack of knowledge, the lack of clinical and basis research, and the need for more research centers throughout the country for diagnosis and treatment and research on the Marfan syndrome and heritable disorders of the connective tissue should be our top priorities.

Thousands of people affected with the Marfan syndrome receive poor medical care, and in too many cases misdiagnosis and mistreatment with fatal consequences. My son died of a ruptured aneurysm at the age of 22. He bled internally for 2 days to his death, undiagnosed.

Flo Hyman, the Olympic volleyball star, died undiagnosed. Chris Patton, basketball star at Temple University, died undiagnosed. There have been thousands of such cases where diagnosis is only learned at autopsy.

Even then, the genetic nature of the disorder is not addressed, and family members are not advised that they themselves may be victims of the disease. There are visible physical characteristics, but there is no test because there is yet no knowledge of what causes the basic molecular defect.

In order to learn its cause, money is needed to support research. In 1987, less than $400,000 was allocated for primary research on the Marfan syndrome. This amounts to less than $10 per person.

The toll taken by illnesses is enormous, both financially and emotionally. Families can be devastated since multiple family members are often affected. In many cases, the wage earner dies leaving the partner with several children and the family in need of ongoing medical care and treatment.

All too often these families are refused medical insurance, and become financially as well as emotionally devastated. We recognize that the development of clinical centers and initiatives for basic research into Marfan syndrome and other rare disorders will cost many millions of dollars.

PREPARED STATEMENT

Whatever the cost, I urge you to meet the challenge by adopting this funding recommendation which will enable NIH to further its efforts in the area of basic and clinical research. Thank you.

[The statement follows:]

STATEMENT OF PRISCILLA CICCARIELLO

Mr. Chairman, members of the Committee, I thank you for the opportunity to speak before you today.

I am Priscilla Ciccariello - Chair of the National Marfan Foundation. The NMF is a non-profit voluntary agency working on behalf of persons and their families affected by the Marfan syndrome, the genetic disorder that needlessly took the life of Olympic volleyball champion Flo Hyman, and my son and husband, and thousands more.

Marfan syndrome is a potentially fatal genetic disorder of the connective tissue characterized by tall stature, long limbs and fingers, scoliosis, cardiac complications, and subluxation of the lenses of the eyes. It is estimated that up to 40,000 people in the United States have this conditon, but for a number of reasons many do not know they have it. President Lincoln, Paganini, and Rachmananoff are among those suspected to have had the Marfan syndrome.

In our concern for this life-threatening and disabling disorder we are strongly supporting the funding currently allocated for the National Institutes of Health because this may help to address three specific concerns of the Foundation:

First, the lack of knowledge about the Marfan syndrome in the public and in the medical profession.

Second, the lack of clinical and basic research on the Marfan syndrome, and

Third, the need for more clinical research centers throughout the country for diagnosis, treatment and research on heritable disorders of the connective tissue.

Thousands of people affected with the Marfan syndrome receive poor medical care and in too many cases misdiagnosis and mistreatment with fatal consequences. My own son died of a ruptured aneurysm at the age of 22; he bled internally for two days to his death. Flo Hyman, the Olympic volleyball star died undiagnosed. Chris Patton, basketball star at Temple University, died undiagnosed. There have been thousands of such cases where diagnosis is only learned at autopsy. Even then the genetic nature of the disorder is not addressed, and family members are not advised that they themselves may be victims of the disease.

Although there are some visible physical characteristics that do lead to a diagnosis of the Marfan syndrome, it is often difficult to diagnosis because the physical characteristics are varied and the severity of expression is wide-ranging. There is no test, because there is yet no knowledge of what causes the basic molecular defect. In order to learn the basic cause of the Marfan syndrome, money is needed to support basic research.

In 1987 less than $400,000 was allocated for primary research on the Marfan syndrome, which amounts to less than $10.00 per person.

Moreover, there is no clinical research on the Marfan syndrome being funded either intra or extramurally by the National Institutes of Health.

Without the basic and clinical research centers, people stricken with Marfan syndrome and other rare genetic disorders have little hope for survival. I refer not only to basic survival but to a quality of life that enables families to survive together. The toll taken by these illnesses is enormous, both financially and emotionally. Families can be devastated since multiple family members are often affected. In many cases the wage earner dies leaving the partner with several children in need of ongoing medical care and treatment. Drug therapies, the only treatment now known, can cost several thousand dollars per year for life. Additionally, the open heart surgery, needed in many cases, costs thousands of dollars. All too often these famlies are refused medical insurance and become financially as well as emotionally devastated.

With the proposed budget for NIH programs, research could be initiated which would eventually save lives and suffering for many thousands of families. Where can we turn if not to the NIH? Without a center at NIH or qualified medical institutions in other parts of the coutnry funded extramurally by NIH, people with Marfan sydrome have little hope for proper diagnosis and care.

We recognize that the development of clinical centers and initiatives for basic research into Marfan syndrome and other rare disorders will cost many millions of dollars. Whatever the cost, I urge you, as the spokesperson for my constituency, to meet the challenge by adopting this funding recommendation which will enable NIH to further its efforts in the area of basic and clinical research.

Senator **Harkin**. So you are saying that there is no funding for research on Marfan syndrome being funded either in the National Institutes of Health or outside?

Ms. **Ciccariello**. That is correct. No extramurally or intramurally. And that funding that amounts to about $400,000 is going for other heritable disorders as well as Marfan syndrome.

Senator **Harkin**. Thank you very much for your testimony. We will see what we can do to correct that.

Ms. **Ciccariello**. Thank you very much for listening.

STATEMENT OF SUE TOLCHIN, PROFESSOR OF PUBLIC ADMINISTRATION, GEORGE WASHINGTON UNIVERSITY, ON BEHALF OF THE CYSTIC FIBROSIS FOUNDATION

Senator **Harkin**. The next is Sue Tolchin of the Cystic Fibrosis Foundation.

Ms. **Tolchin**. Thank you, Senator Harkin, members of the committee. I am Professor Susan Tolchin from George Washington University. I am professor of public administration. I am here today representing the Cystic Fibrosis Foundation, specifically Bob Dresing, who is the president of the Cystic Fibrosis Foundation.

I am also here because I am a mother of a son with cystic fibrosis. My son, Charles, age 19, has cystic fibrosis. He represents more than one-half of the adults who survive into adulthood. When he was diagnosed at the age of 5, the life expectancy was 12.

Now it is well into the 20's, and we hope that as the research progresses it will continue on so that someday we will put this disease out of business.

Now, thanks to a combination of forces, we have reason for new hope. We have discovered candidate genes, which means we are within sniffing distance of discovering the gene that causes this genetic lung disease, affecting now 30,000 patients, and is the leading killer of all of the genetic diseases.

We thank Congress for its support, and we ask for your continuing support. Before there was Federal support, the Cystic Fibrosis Foundation, which is a parent-run voluntary organization, went out and raised $15 million on its own specifically to fund our own research.

Through that money we funded 13 multidisciplinary centers at a rate of $1.5 million each. And it was those research centers that gave us the research breakthroughs that have given us new hope and new reason for excitement for the future.

Last year, thanks to this committee and the Congress, NIH was able to support, was able to start to match us and help us support four more centers which will continue this vital research.

It is the intent, it was the intent of the committee to support six more centers in fiscal years 1988, 1989, and we ask that this report language to this affect be included in this year to help NIH continue its intramural and extramural programs for research into this disease.

This way the foundation will be able to reinvest its dollars in new projects to continue this research. We have set a new goal of $10 million for more new centers, and we hope that at one of these centers, one of the oldest centers, we will be able to come close to or at least continue the research which will help us identify the gene which will lead to a cure for this disease.

As a parent, I feel very fortunate that this foundation, the Cystic Fibrosis Foundation, has been so successful in its own fundraising, and I think that I am also very heartened by the fact that Congress has begun to share what we hope will be one of the greatest scientific breakthroughs of the 20th century, discovery of the cystic fibrosis gene.

This will alleviate the needless suffering of 30,000 patients and their families, not to mention the excess, the cost of $300 million in health costs to pay for the ravages of this disease.

PREPARED STATEMENT

We also want to thank you for continuing your vigilance and oversight over the intrusions into NIH intramural research support. The research is moving rapidly. We want to put this disease out of business, and I am confident that we will with your continued support and your help. Thank you very much.

[The statement follows:]

STATEMENT OF ROBERT DRESING, PRESIDENT, CYSTIC FIBROSIS FOUNDATION

My name is Robert Dresing, and I am president of the Cystic Fibrosis Foundation and the father of a son with cystic fibrosis (CF).

I come before you to thank you for your support thus far and to share how our CF research centers are continuing to make important strides toward eliminating the nation's number one fatal genetic disease. These centers are providing an optimism that was unknown thirty years ago, when most children died of the disease before they reached age five.

In turning 21 this year, my own son, Rob, has joined the more than half of individuals with CF who now survive into adulthood -- and who represent what research advances can offer. Yet this same group of adults also symbolizes how much more the science must provide: at the time when they become vital, contributing members to our society, the thick mucus that clogs their digestive systems and lungs threatens increasing damage and death.

Fortunately, we now have the best vehicle that has ever existed for bringing about change to CF -- our nationwide network of multidisciplinary research centers. As one of our research center directors commented, "CF need not be a fatal disease if we can identify ways to intervene in those aspects which are most life-threatening."

Cystic fibrosis research centers are doing precisely that. Indeed, they have already developed a working hypothesis that links the diverse symptoms of the disease into one overriding framework, based on the documented abnormal ion movement in CF-affected cells. With the knowledge that treatments have been developed for ion transport problems in certain heart and kidney conditions, our scientists are working to identify the basic defect -- the precise reason for this abnormality in CF.

CF scientists also have pinpointed the CF gene's location to chromosome seven, where they are exploring several candidate genes in order to identify the gene itself. In a further leap, the first successful gene insertion experiments in the world occurred this past year at one of our research centers, beginning the path for what may one day be the ability to replace defective genes with normal ones.

Your role in this progress goes back to the very origin of these research centers: the study which you, the members of Congress, mandated on the status and future directions of CF research.

That study became the foundation for the work we have accomplished to date. In pointing to the need for a series of CF research centers, the study emphasized how scientists from diverse fields would have to work together to unravel the complexities of CF. Because so much was yet unknown about CF, the report stressed that these centers would need to focus on preliminary studies through seed grants, enabling scientists to form hypotheses and build data. Your study stated that, once these steps were accomplished, scientists would be equipped to compete for major NIH support.

Although federal funds were not available to initiate these research centers, we accepted the challenge to fulfill the recommendations on our own and set a goal to raise $15 million in five years. Never before had a private foundation taken the initiative to underwrite a research program of this magnitude through private donations.

To date, we have awarded thirteen centers with commitments averaging $1.5 million each. Selected through a stringent peer review process, the centers are located at leading universities and research institutions. Furthermore, we have recommitted ourselves to raising another $10 million in three years to provide initial awards for several additional centers.

Mr. Chairman, we must thank you for responding last year to the need for funding of these centers. If it wasn't for the leadership you, this Committee and the Congress showed, the NIH would not be on track in taking a comprehensive approach toward these centers. In allocating funds to the NIDDK and NHLBI for support of CF research centers, the Congress' initiative is expected to provide four much-needed new awards in October.

This federal funding and increased NIH involvement will certainly help. However, we must anticipate that the tremendous potential that exists in other centers will not be supported through this initial allocation. While we are dedicated to raising as much private CF research support as we can, we cannot possibly provide the expanded support that these centers require to reach their full potential. We must be able to count on an intensified public-private partnership -- and on the NIH's ability to take over the funding for these centers after they have proven themselves. You have shown that you recognize the wisdom of this symbiotic relationship; we can add only that the last year's advances make federal support of these centers even more crucial.

Therefore, we urge you to ensure comprehensive support for additional research centers by incorporating the attached report language into the Committee's report. In addition, we emphasize our support for an overall NIH budget of $8.2 billion for a balanced program in grants, training and clinical trials, with additional funds provided for equipment and facilities.

We also must express our concern for the NIH's intramural program. Over the years, this premier institution has made substantial contributions to biomedical research. Yet its continued viability is threatened by the activities of a variety of government agencies. The Congress needs to secure the intramural program's future through special salary programs, sufficient manpower, and protection from unnecessary interference with the progress of science. These measures are urgently needed.

As for the CF research centers, we only come to you this second time because the scientific opportunities keep expanding. The annual bill of $300 million to those with this disease, not to mention the suffering of their families -- all of these considerations rest upon what science can offer for change.

Yet, ultimately, our limitation to halting this disease does not seem to be in the science. Our centers continue to prove that if you bring enough good scientists together with sufficient resources, they will stretch the technologies to the next step. Our greatest limitation appears to be the funding of this work.

Through your mandated study, we found and polished what has become the ideal strategy for making advances against CF, but we have other centers in our program which deserve comprehensive support as well. With your support, the CF Foundation can continue to reinvest its dollars where we have proven our strength: starting the centers, building the research teams, and bringing the initial results -- that assure NIH support will fund only the most excellent of investigations. While we continue to extend our own commitment, we must turn to you who can enable our research centers to transform CF into a former fatal disease. Thank you for your consideration.

The Committee commends both the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung and Blood Institute (NHLBI) for promptly initiating a Cystic Fibrosis Centers program. It was the intent of the Committee that a total of up to six centers begin in fiscal 1988 and 1989. This program shall continue in an effort to create an effective public-private funding mechanism to support the highly effective cystic fibrosis research network across the country.

Senator Harkin. Sue, thank you very much. I know you in a different life. I am honored that you are here on this.

Ms. Tolchin. Thank you. I am honored that you are chairing. I am an admirer of yours in other fields.

Senator Harkin. Let me ask you, the Cystic Fibrosis Foundation is asking, do we have report language?

Ms. Tolchin. We are asking you to include report language that enables, that mandates that NIH spend a certain amount of money on cystic fibrosis research.

If this is in the report language, no one can come in and tell NIH to spend it on something else. We are hoping that the Congress, it was this committee last year that enabled us, that put it in the report language last year. And we want to continue that this coming year, to continue the research support.

Senator Harkin. Well, in talking to counsel, I am informed that we have looked at this, and I think we will be able to do it. Let me rephrase that. We will be able to do it.

Ms. Tolchin. Wonderful. On behalf of all of us, I thank you.

STATEMENT OF DR. ANTHONY N. DEMARIA, PRESIDENT, AMERICAN COLLEGE OF CARDIOLOGY

Senator Harkin. Next is Dr. DeMaria, representing the American College of Cardiology.

Dr. DeMaria. Senator Harkin and other committee members, I am Dr. Anthony DeMaria. I am the president of the American College of Cardiology, which is a 16,000-member, nonprofit professional medical society dedicated to fostering optimal cardiovascular care and disease prevention.

I welcome the opportunity in light of this mission to address you about the funding of the NHLBI. I would like, with your indulgence, to depart from the formal presentation which has been submitted in writing to you, and to present a case that I think illustrates many of the issues that we think are of relevance in funding NHLBI.

And it deals with a patient, a 45-year-old male, who presented approximately a couple of weeks ago to a rural Kentucky hospital with an acute myocardial infarction. The patient was immediately administered a clot-dissolving drug, was put in a helicopter, transported to a major city, where an angiogram revealed that the accluted vessel had been recanelized but still had a major acclusion causing lack of blood flow.

The patient then had a balloon dilation which relieved this problem, but continued to have difficulties because of some other lesions, had radionuclide stress tests and underwent a coronary bypass procedure which rendered the patient asymptomatic and functional.

This case illustrates, I believe, a lot of the factors we deal with in heart disease. No. 1, incredible incidence of the problem, 53 million Americans, many of them in the prime of life and the most productive years.

No. 2, the incredible insights in basic science, such as thrombosis and clot-dissolving drugs. No. 3, the translation of this basic science to the clinical setting so a patient gets treated, particularly a patient who in former times would not have access to this kind of treatment.

And, last, the high technology, the radionuclide test, the angioplasty, and the major steps that cardiology is making in that direction. We have made a lot of progress, but there is an enormous need for further knowledge and advances.

We need to know what causes atherosclerosis. What is it that initiates the plaque-forming process in the coronary arteries? Why do the plaques go from being quiet to suddenly resulting in an acute syndrome such as a myocardial infarction or unstable anginopectoris?

We need to have better diagnostic modalities to tell us where the heart muscle is viable, or whether it has been totally destroyed, whether it is functioning in an appropriate fashion.

And last, we need better therapeutic modalities such as left ventricular assist devices and artificial hearts for those patients in whom the standard pharmacological therapy is ineffective.

What will it take to do this? I believe that it will take more investigators primarily. We need to have more investigators, we need to have more competing and noncompeting research grants.

PREPARED STATEMENT

We need the research centers, and therefore the American College of Cardiology calls upon your committee to support their recommendation of the total funding of $1.187 billion for the National Heart, Lung and Blood Institute, which will enable all of these programs to be carried out. Thank you very much for the opportunity to testify.

Senator HARKIN. Thank you very much, Dr. DeMaria.

[The statement follows:]

STATEMENT OF DR. ANTHONY N. DeMARIA

Mr. Chairman, and members of the Subcommittee, I am Dr. Anthony DeMaria, Professor of Medicine and Chief of Cardiology Division, University of Kentucky. I am very pleased to be with you today representing the American College of Cardiology, of which I am currently President. The College is a 16,000 member non-profit professional medical society and teaching institution whose mission is to foster optimal cardiovascular care and disease prevention through professional education, promotion of research, and leadership in the development of standards and formulation of health care policy.

National Heart, Lung, and Blood Institute

In keeping with our mission we wish to confirm our strong and ongoing interest in supporting the need for high quality medical research in the areas of prevention, diagnosis and treatment of cardiovascular disease. And the National Heart, Lung, and Blood Institute (NHLBI) is critical in sustaining that effort. In furtherance of this end, we urge the Subcommittee to commit funding at the highest reasonable level to NHLBI.

NHLBI has estimated that at least 58 million Americans suffer from the consequences of heart disease, and of these, 43 million are under 65 years of age. Almost half of all deaths in 1985 were attributed to cardiovascular diseases, with the economic cost to the nation reaching $110 billion annually half due to health expenditures and half for lost productivity.

The Administration's budget request for FY 1989 for NHLBI is $1.054 billion, an increase of 9% over FY 1988. We applaud the fact that the Administration has recognized the importance of this investment and has requested an increase, but the overall size of the President's request for the Institute should raise concern. Consequently, we join our colleagues in the medical research community in calling for a FY 1989 appropriation level of $1.187 billion.

I would like to address the needs of NHLBI and the patient community it serves within the context of the specific categories of research currently underway.

Research Project Grants (competing and non-competing)

NHLBI supported 966 competing research project grants in FY 1987, the last year for which final data are available. It is estimated that the President's proposed budget ($681 million) would support only 828 competing grants in FY 1989 and that competing research grants would be cut by 13.5% and non-competing grants, by 11.4%.

Mr. Chairman and members of the Subcommittee, it remains a matter of grave concern to me and to the community I represent that NHLBI can fund only about one-third of all the meritorious research grant proposals submitted. The missed opportunities for insight into heart disease represented by the fact that 66% of worthy applications go unfunded is hard to explain when this country will see one million people die this year from cardiovascular disease.

Research project grants have been responsible for countless dramatic breakthroughs as well as incremental improvements in our understanding of the prevention, diagnosis and treatment of cardiovascular disease. From the effects of aspirin on prevention of heart attacks, to the use of Tissue Plasminogen Activator (tPA) in the treatment of acute myocardial infarction, these grants have made a significant improvement in our quality of life.

We believe that the Congress should go beyond this minimal level of funding and provide $803 million for research project grants. This funding level would permit NHLBI to fully fund non-competing research project grants in FY 1989. It would also allow support of an additional 323 competing research grants, beyond the 1988 level, for a total of 1178 competing grants. This would permit the Institute to finance about 45% of approved competing applications.

Specialized Centers of Research (SCOR's)

As a multidisciplinary program targeted to specific disorders, the Specialized Research Center program was instituted in 1970 to advance basic knowledge and to discover the most effective techniques and methods of clinical management and prevention in such areas as arteriosclerosis, hypertension and ischemic or coronary heart disease. There are currently 60 Specialized Centers of Research in operation with some 1200 scientists receiving support.

The President's proposed budget for the program ($90 million) would require reductions of approximately 11.3% in existing SCORs. There is a critical need to fully fund ongoing efforts and undertake the commitment to two additional SCORs already in the planning stage. We ask for full funding of existing and planned Specialized Centers of Research and a fulfillment of the commitments to new programs in such critical areas as coronary disease, heart failure, and congenital heart disease.

Research Career Awards

The NHLBI has had a longstanding commitment to programs to encourage research careers. The Institute currently administers 410 research career awards at a cost of $26.3 million. The President's proposed budget would freeze the number of awards, limiting the dollar increase to only a half million dollars for inflation.

Research career awards are crucial to the mission of the NHLBI. They assure that there is an adequate number of well trained researchers for the next generation. They also keep the NHLBI programs on the cutting edge of technology and intervention strategies.

We think it would be unfortunate if the NHLBI's effort to encourage young investigators were arrested in this way.

At a minimum, Congress should grant an additional $5 million above the President's request to this effort. This would fund 500 career awards.

Other Research Grants

Research grants are a very important element in the Institute's efforts in the areas of education, behavorial modification strategies, and environmental and organizational strategies designed to improve prevention or management of disease. Regrettably, there has been no funding available for new demonstration and education projects since FY 1985.

The 1988 appropriation for this category was $13.7 million, a freeze from last year's funding. The President's budget request for FY 1989 is $13.5 million, a reduction of $200,000 from FY 1988. We recommend that Congress provide increasing funding in this effort.

National Research Service Awards (NRSA)

A recent survey of cardiology training directors by the American College of Cardiology revealed that 80% of the directors believe that additional researchers are needed in our field. Physician researchers are able to bring a clinically relevant perspective to basic research and are therefore critically important to the success of our national research effort.

The President's proposed budget would provide $40.3 million for the research service programs, essentially a virtual continuation of the freeze that has been imposed since FY 1987. This vital effort should receive, at a minimum, an additional $2 million to provide needed stability to this program.

If possible, we would strongly recommend devoting $54.1 million to this program. This would allow for an increase of 551 positions in this program to a level of 2,000 awards. The need for training of our future medical researchers is often overlooked, yet may indeed be the most important facet of our biomedical research effort.

Research Contracts

Research contracts are utilized by NHLBI for purposes of developing or applying new knowledge to further the science of medicine. In addition, new medical devices may be tested, screened or evaluated through a research contract.

FY 1988 appropriations for this program were $79.3 million, which supported 243 contracts. The President's budget request would fund an additional 10 contracts at a total level of $89.2 million. We recommend that Congress consider providing sufficient funds to support an increased level of activity in this area. Research contracts are very important in the effort to develop new and life-saving technology for use in the fight against heart disease.

Intramural Research

Among the intramural research projects of concern to the American College of Cardiology is the newly established Laboratory of Cardiac Energetics, dedicated to developing a better understanding of the cellular processes that enable the heart to work. This program uses and develops state-of-the-art, non-invasive magnetic resonance and optical spectroscopy to evaluate the entire cardiac energetics process, blood flow, metabolism and blood pumping mechanism in living systems to determine the key regulatory steps in this process. Ultimately, this science will lead to the development of new strategies for the prevention, diagnosis and treatment of heart disease.

The FY 1988 appropriation for intramural research was $66.8 million. The President's budget request is for $69.4 million. We recommend that Congress provide additional funds as needed to assure the continuation of the important intramural work underway, including the Laboratory of Cardiac Energetics, and for the purchase of additional needed equipment.

Research Management and Support

Appropriations for research management and support are used not only for the overall management of the Institute, but also for its important and highly effective education programs. These include the very successful National High Blood Pressure Education Program, the National Cholesterol Education Program, and the NHLBI Smoking Education Program. These efforts have successfully helped millions modify unhealthy habits by training physicians and allied health professionals to serve as intervenors.

The FY 1988 appropriations for these efforts was $41.6 million. The President's budget would raise this level to $44 million. We think a significant additional investment should be considered for these important public health initiatives.

Construction

In FY 1988, NHLBI received no new funds for construction grants. Today, there is a clearer idea of the vital need for construction dollars for research institutions. Construction and renovations of facilities to comply with safety standards in AIDS research, for animal safety and for research in developing institutions are priority items requiring some federal and some private investment.

We recommend that a modest investment be made for construction to assist research institutions in the effort to comply with federal standards in performing high quality biomedical research.

National Library of Medicine

The American College of Cardiology also takes this opportunity to voice continued strong support for the work of the National Library of Medicine. The ACC and participants in the College's educational programs benefit directly from the Library's work through the ability to access four million medical citations through the Library's Medline computer retrieval system.

In addition to its vast collections of medical literature, the Library also provides a program of grants for medical libraries, for training, and for research in biomedical communications.

Mr. Chairman, I appreciate the opportunity to appear before this distinguished Subcommittee today. On behalf of my colleagues in cardiovascular medicine, I wish to thank the members of the Subcommittee for their consistent support of the NHLBI and your help with our efforts to restrain the nation's number one killer - heart disease.

STATEMENT OF DR. J. ALFRED RIDER, PRESIDENT, CHILDREN'S BRAIN DISEASES FOUNDATION

Senator HARKIN. We will now move on to the National Institute of Neurological and Communicative Disorders and Stroke. Dr. J. Alfred Rider representing the Children's Brain Diseases.

Dr. RIDER. Senator Harkin and committee members and guests, I am Dr. J. Alfred Rider, president of the Children's Brain Diseases Foundation based on San Francisco, CA.

It is a pleasure to testify here again. The Children's Brain Disease Foundation is a nonprofit organization and is devoted to the study of children's brain diseases. Our first priority, however, has been Batten disease.

Now, Batten disease is a neurological disorder which may have an incidence as high as 1 in 12,500 births. It is probably the most common type of neurogenetic storage disease in children.

Although there are several subtypes, the usual disease manifests itself in previously normal children at the approximate age of 5 to 10, and is characterized by a slow progression of clumsiness, stumbling, and failure of vision, seizures, changes in personality, and dropping of scholastic grades.

The disease eventually leaves them totally disabled and unable to care for themselves, and usually ends in death in the late teens or twenties and rarely into the thirties.

The changes which occur in the brain in these children are quite similar to many of the changes in the aging person. Thus effective treatment for Batten disease may also allow us to alter the aging process of senility in all humans.

The basic cause of the disease may be related to a defect in the enzyme system in the brain. In the last year, significant advances in research have been made. Batten disease has been diagnosed by amniocentesis, and a relatively simple blood test shows promise and respect to those with the disease and carriers.

Research is now being directed toward getting additional evidence and proof so that these techniques will be generally available to the public. Research must continue to be directed toward not only prevention but also treatment.

It would appear that gene splicing techniques and also agents designed to block the accumulation of the abnormal enzyme and produce or enhance its degradation could be effective.

We have always supported the budget presented by the National Institute of Neurological and Communicative Disorders and Stroke. We are very pleased that your committee recommended an appropriation of approximately $550 million for fiscal year 1988.

The following words appeared in the 1988 House appropriation bill.

> The committee learned that in spite of last year's recommendation requesting research on Batten disease, little research was funded in 1987. Therefore, it encourages the National Institute of Neurological and Communicative Disorders and Stroke to again solicit applications for grants of quality for Batten disease research.

Therefore, we were disappointed to learn that only about $150,000 was spent directly on Batten disease in fiscal year 1987. We recommend that the above same wording be adopted in this year's appropriation and that to this be added, "and to fund up to $1 million per year for 5 years for research on Batten disease."

This is a small price to pay to solve a disease which is draining our national financial resources to the tune of approximately $250 million per year based on 3.7 million babies born in 1987, 300 born with Batten disease, and a treatment and maintenance cost on the average of $50,000 per year per lifetime of the child.

If these funds are provided, the chance of development of a specific treatment program in the near foreseeable future appears to be excellent.

Now, the Children's Brain Disease Foundation started out funding research, giving seed money to various faculty members and researchers all over the world.

In the present time we are proud that we have over 47 institutions and people working on this disease, and we are confident that we can solve this in the near future, so that there will be effective treatment, such as with diabetes, you can give people insulin and they can live a long normal life.

PREPARED STATEMENT

Most of these neurological disorders are boiling down to an enzyme defect, which should be able to be replaced or modified. And we think that we are making great breakthroughs, and we need the funds from the NIH to accomplish this. Thank you kindly.

[The statement follows:]

STATEMENT OF DR. J. ALFRED RIDER

I am Doctor J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. It is a pleasure to testify before the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations and support the requests of the National Institute of Neurological and Communicative Disorders and Stroke.

I speak today specifically with reference to research funding for Batten disease. This is a neurological disorder which has an incidence as high as 1 in 12,500 births, similar to other genetic disorders. It is probably the most common neurogenetic storage disease in children.

Although there are several sub types, the usual disease manifests itself in previously normal children at the approximate age of 5 to 10 and is characterized by a slow progression of clumsiness, stumbling and failure of vision, seizures, changes in personality and dropping of scholastic grades. The disease eventually leaves them totally disabled and unable to care for themselves and usually ends in death in the late teens or early twenties and rarely in the thirties.

One of the earlier theories on the cause of these disorders was that there was an abnormality in the peroxidase enzyme system in the brains of children with Batten disease which produced an accumulation of a yellow pigment, ceroid lipofuscin, in brain cells, which resulted in a marked loss of brain cells or neurons. The loss of brain cells is reflected in the clinical picture with intellectual, neurological and opthalmological impairment. These changes are quite similar to the changes that take place in all brains as they age. Thus, effective treatment for Batten disease might delay the normal aging process.

Recent studies by Doctor Siakotos et al suggest that 4 hydroxy nonenal may play a significant role in the etiology of Batten disease. Thus, continued research must be directed toward not only prevention, but also treatment.

Prevention

Without advances in treatment, carrier detection alone can reduce the incidence of the disease by screening families and relatives with a history of Batten disease and noting the individuals who are carriers. Genetic counseling of these individuals, especially premarital screening, may reduce the incidence of affected children in the future.

The biochemical test for Batten disease may also be employed for testing cells obtained by amniocentesis of expectant mothers, where both parents are carriers. Positive results may require genetic counseling and a consideration of choices available to the parents.

Treatment

At the present time, there is no specific treatment for Batten disease. Treatment is largley symptomatic. In the event the newly discovered pathway (cytotoxic aldehyde-4 hydroxy nonenal) is the specific pathogenetic lesion in Batten disease, the effectiveness of drugs or diet supplementation intended to change the course of the disease can be monitored in the animal model. Hopefully, this screening procedure will quickly determine the most efficient means of inhibiting the disease in specific biochemical pathways. When a simple reliable blood test is generally available, the problem of identifying and characterizing the genetic defect in different types of Batten disease will be easy.

It is too early to know whether gene therapy may be possible in Batten disease, but once the genetic defect is known, e.g., the production of a toxic product, then therapy can be directed towards increasing the metabolism or blocking the formation of that toxic product by diet or drug therapy. If the gene directs the production of an altered or defective enzyme or hormone, therapy can be directed toward enzyme or hormone replacement. Methods of enzyme or substrate replacement include the transplantation of embryonic cells to specific areas of the brain in a disease which occurs as a focal lesion.

Other types of gene therapy include transfer of normal genes to defective white blood cells from affected patients and the reintroduction of the altered blood cells to the patient. This procedure would, if successful, provide an increase in normal enzymes or substrate in affected individuals.

In addition, since some types of Batten disease have an adult or delayed onset, the gene may trigger or initiate a process which causes the disease. Therefore, if one can delay this process further, then the onset of the disease can be programmed to very late in life, e.g., 80 years of age.

The Children's Brain Diseases Foundation is doing the best it can to stimulate research on Batten disease. We are continuing to sponsor research all over the world.

Unfortunately, our abilities to raise money from private sources are limited, and the major monies must come from NIH. There are over forty seven principal investigators from major universities, medical centers and institutes throughout the world interested in various phases of research pertaining to Batten disease. (See Addendum A.) These researchers are in dire need of monies to continue their work.

We have always supported the budget presented by the National Institute of Neurological and Communicative Disorders and Stroke. We were very pleased that your Committee recommended an appropriation of $550,172,000 for fiscal year 1988. Although it is difficult to get an exact figure for monies directly spent on Batten disease since grants have multiple purposes, we were disappointed to learn that only about $150,000 was spent directly on Batten disease in FY 1987. The estimate for FY 1988 is only slightly more. We,therefore, would encourage that the same wording be included in the 1989 House Appropriation Bill namely:

> "The Committee learned that, in spite of last year's recommendation requesting research on Batten disease, little research was funded in 1987. Therefore, it requests that the Institute actively solicit applications for grants of quality for Batten disease and report on progress with respect to Batten disease at next year's hearings."

To this, we would appreciate your committee adding the words "and to fund up to $1,000,000 per year for five years for research on Batten disease."

This is a small price to pay to solve a disease which is draining our national financial resources to the tune of approximately 250 million per year based on 3.7 million babies born in 1987; 300 born with Batten disease and at a treatment and maintenance cost of $50,000 per year per life time of a child.

If these funds are provided, the chances of the development of a specific treatment program in the near forseeable future appear to be excellent.

Summary of Recommendations

Batten disease is a neurological disorder which may have an incidence as high as 1 in 12,500 births. It is probably the most common type of neurogenetic storage disease in children. Although there are several sub types, the usual disease manifests itself in previously normal children at the approximate age of 5 to 10 and is characterized by a slow progression of clumsiness, stumbling and failure of vision, seizures, changes in personality and dropping of scholastic grades. The disease eventually leaves them totally disabled and unable to care for themselves and usually ends in death in the late teens or twenties and rarely, into the thirties. The changes which occur in the brain in these children are quite similar to many of the changes in the aging person. Thus, effective treatment for Batten disease may also allow us to alter the aging process of senility in all humans.

The basic cause of the disease may be related to a defect in an enzyme system in the brain. In the last year, significant advances in research have been made. Batten disease has been diagnosed by amniocentesis and a relatively simple blood test shows promise in respect to those with the disease and carriers. Research is now being directed toward getting additional evidence and proof so these techniques will be generally available to the public.

Research must continue to be directed toward not only prevention, but also treatment.

It would appear that gene splicing techniques and also agents designed to block the accumulation of the abnormal enzyme and produce or enhance its degradation could be effective.

We have always supported the budget presented by the National Institute of Neurological and Communicative Disorders and Stroke. We were very pleased that your Committee recommended an appropriation of $550,172 million for fiscal year 1988.

The following wording appeared in the 1988 House Appropriation Bill:

> "The Committee learned that, in spite of last year's recommendation requesting research on Batten disease, little research was funded in 1987. Therefore, it encourages the National Institute of Neurological and Communicative Disorders and Stroke to again solicit applications for grants of quality for Batten disease research."

Therefore, we were disappointed to be learn that only about $150,000 was spent directly on Batten disease in fiscal year 1987.

Thus, we recommend that the above same wording be adopted in this year's appropriation bill and to this be added "and to fund up to $1,000,000 per year for five years for research on Batten disease."

> "The Committee learned that, in spite of last year's recommendation requesting research on Batten disease, little research was funded in 1987. Therefore, it encourages the National Institute of Neurological and Communicative Disorders and Stroke to again solicit applications for grants of quality for Batten disease research and to fund up to $1,000,000 per year for five years for research on Batten disease."

This is a small price to pay to solve a disease which is draining our national financial resources to the tune of approximately 250 million dollars per year based on 3.7 million babies born in 1987; 300 born with Batten disease and at a treatment and maintenance cost of $50,000 per year per life time of a child.

If these funds are provided, the chances of the development of a specific treatment program in the near forseeable future appear to be excellent.

Addendum

1. Doctor Donald Armstrong
   Kuwait University, Faculty of Allied Health Sciences and Nursing
   Relationships of Peroxidase to Batten's disease
   Canine Retinal Degeneration: An Approach to Therapy
   Peroxidase Deficiency and Peroxidase Regulating Enzyme
   Peroxidase Activity in Human and Canine Ceroid-lipofuscinosis, with Special Emphasis on the Eye

2. Doctor Robert J. Baumann
   Department of Neurology
   University of Kentucky and Section on Epidemiology OBE, Office of the Director, NINCDS, Bethesda, Maryland
   Leukocyte Ultrastructure

3. Doctor M. J. Bennett
   Sheffield, UK
   Batten's disease: A Previously Unrecognized Dyslipoproteinaemia

4. Doctor Milton Brightman
   Lab. of Neuropathology and Neuroanatomical Sciences, NINCS & National Institutes of Public Health/Department of Health and Human Services
   Transport of Horseradish Peroxidase Across Blood Brain Barrier

5. Doctor S. Carpenter
   Montreal, Canada
   Biopsy Diagnosis in the Varieties of Ceroid-lipofuscinosis--Criteria and Pitfalls

6. Doctor Glyn Dawson
   Associate Professor, Departments of Pediatrics & Biochemistry, The University of Chicago
   Pre-Natal Diagnosis and Enzyme Replacement Therapy
   Approaches to the Detection of Neuronal Ceroid lipofuscinosis in Cultured Skin Fibroblasts
   Abnormal Cathepsin Activity in Batten's disease

7. Doctor T. L. Dormandy
   Whittington Hospital, London
   Free Radicals and Lipopigments

8. Doctor Edward Dratz
Department of Chemistry, Montana State University
Measurement of Fluorescent Lipopigment, Peroxidized Fatty Acids, Vitamin E, Effects of Antioxidants on Lipopigment Formation

9. Dr. P. R. Dyken
Mobile, Alabama
Reconsideration of the Entity of Ceroid-lipofuscinosis (NCL). Is it a Disease or a Syndrome?

10. Doctors Graig E. Eldred and Martin L. Katz
University of Missouri School of Medicine
Lipofuscinogenesis in the Retinal Pigment Epithelium

11. Dr. Y. Eto
Tokyo, Japan
A Clinical and Biochemical Exploration of Neuronal Ceroid-lipofuscinosis in Japanese Patients

12. Doctor R. M. Gardiner
John Radcliffe Hospital, Oxford, England

13. Doctor Paul Glees
University of Cambridge, Anatomy School, Cambridge
Electron Microscopic Studies on Neuronal Lipofuscin:Accumulation and Removal
The Effects of Centrophenoxine in the Central Nervous System

14. Doctors Hans H. Goebel and E. Dahme
Division of Neuropathology, University of Gottingen
The Ultrastructural Spectrum and Diversity of Lipopigments in the Neuronal Ceroid-lipofuscinosis
Neuronal Ceroid-lipofuscinosis in the Dalmatian--a New Animal Model for Human Neuronal Ceroid-lipofuscinosis

15. Doctor John M. C. Gutteridge
Division of Antibiotics, National Institute for Biological Standards and Control, Holly Hill, Hampstead, London
Fluorescent Products of Phospholipid Peroxidation: Formation and Inhibition on Model Systems

16. Doctor N. A. Hall
London, UK
Accumulation of Dolichol-linked Oligosaccharides in Ceroid-lipofuscinosis

17. Doctor Egill Hansen
Department of Opthalmology, Rikshopitalet, The National Hospital, University of Oslo, Norway
The Significance of Psychophysical and Electrophysical Methods in the Diagnosis of Juvenile Neuronal Ceroid-lipofuscinosis

18. Doctor Ann Harden
Department of Clinical Neurophysiology, the Hospital for Sick Children, London
Neurophysiological Studies in Children with so-called Neuronal Ceroid-lipofuscinosis

19. Doctor Denham Harman
The University of Nebraska Medical Center
Brain Lipid Composition

20. Doctor K. U. Ingold
Associate Director, National Research Council of Canada, Division of Chemistry
Resistance to Oxidation and the Natural Antioxidant Levels in Membranes from Human Cells

21. Doctor Gunde Egeskov Jensen
The Laboratory of Biochemistry and Toxicology, the Institute of Biology and Chemistry, University of Roskilde, Denmark
Glutathione Peroxidase Activity in Leucocytes, Erythrocytes and Serum from Juvenile Form of Neuronal Ceroid-lipofuscinosis

22. Doctor R. D. Jolly
Department of Veterinary Pathology and Public Health, Massey University, Palmerston North, New Zealand
Ceroid-lipofuscinosis: The Ovine Model Studies on Mannosidosis and Ceroid-lipofuscinosis in Cattle, Sheep and Dogs

23. Doctor Edwin Kolodny
Associate Director, Eunice Kennedy Shriver Center of Mental Retardation, Inc., Waltham, Massachusetts
Pathogensis of the Neuronal Ceroid-lipofuscinosis
The Clinical Classification of Neuronal Ceroid-lipofuscinosis Subtypes

24. Doctor Nils Koppang
Veterinaerinstuttet, Oslo, Norway
Histochemical Evidence of Lipid Peroxidation in Canine Ceroid-lipofuscinosis
The English Setter with Ceroid-lipofuscinosis: A Suitable Model for the Juvenile Type of Ceroid-lipofuscinosis in Humans

25. Doctor P. M. MacLeod
Kingston, Canada
The Prenatal Diagnosis of Jansky-Bielschowsky Disease During the Second Trimester

26. Doctor Martin Maltempo
Assistant Professor of Physics, University of Colorado Medical Center
Monitoring of Peroxidase and Free Radicals in Canine Retinal Tissue Subject to a Degenerative Disease in which there is an Accumulation of Pathologic Lipopigments of the Ceroid Type: A Model for Batten's disease

27. Doctor Jaime Miguel
NASA, Ames Research Center, Moffet Field, CA
Analysis of Pigment Lipofuscin

28. Doctor Sakkubai Naidu
Baltimore, MD
Selenium Therapy in Ceroid-lipofuscinosis

29. Doctor Erling Gronvold Olsen
University Eye Department, Rikshospitalet, University of Oslo
Fluorescein Angiography in Ceroid-lipofuscinosis

30. Doctor D. Palmer
Palmerston North, New Zeland
Chemical Analysis of Isolated Pigments from Ovine Ceroid-lipofuscinosis

31. Doctor Vital Patel
Assistant Professor of Pathology, Indiana University School of Medicine
Antioxidant Treatment of Batten's Disease

32. Doctor Alan K. Percy
Associate Dean, Office of Research, Charles R. Drew Post-graduate Medical School, Los Angeles
Salutory Effect of Selenium, Erythrocyte Glutathione Peroxidase

33. Doctor Michel Philippart
Neuropsychiatric Institute, University of California, Los Angeles
Treatment of Batten's disease with Antioxidants
Diagnosis and Treatment of Typical and Atypical Forms of Ceroid-lipofuscinosis

34. Doctor Mark Poznansky
Associate Professor of Pathology, University of Alberta
Enzyme Replacement and Enzyme Engineering

35. Doctor Raju Pullarkat
New York State Institute for Basic Research in Mental Retardation, Staten Island, New York

Lipopigments in Aging and in Ceroid-lipofuscinosis
Docosahexaenoic Acid Levels in Brains of Various Forms of ceroid-lipofuscinosis
Oligosaccharyl Diphosphodolichols in Ceroid-lipofuscinosis

36. Dr. P. Santavori
Helinski, Finland
Fifteen Years Experience with Antioxidant Therapy in the Treatment of NCL Disorders

37. Doctor Julius Schultz
Director, Pananicolaou Center Research Institute, Miami,Florida
Discovery and Characteristics of Leukocyte Peroxidase and the Purification and Administration to Animals

38. Doctor Gunther Schwendemann
Division of Neuropathology, University Hospita Eppendorf, Hamburg
Diagnosis of Juvenile Ceroid-lipofuscinosis by Electron Microscopy of Lymphocytes and of Rectal, Skin and Sural Nerve Biopsy Tissue

39. Doctor A. N. Siakotos
Professor of Pathology, Indiana University Medical Center
Development of a Reliable Blood Test for Batten's disease
Recent Developments in the Isolation and Properties of Auto-Fluorescent Lipopigments
The Neuronal Ceroid-lipofuscinosis: New Biochemical Findings

40. Doctor P. E. Spoerri
Department of Histology and Neuroanatomy, University of Gottingen
Ultrastructural Age Changes in Neurons and Myocardium in Culture
The Effects of Centrophenoxine on Age Pigment

41. Doctor S. K. Srivastava
Department of Human Biological Chemistry & Genetics, The University of Texas Medical Branch
Purification and Properties of Leukocyte Peroxidase
Biochemical Studies in Neuronal Ceroid-lipofuscinosis

42. Doctor Al Tappel
Division of Food Science & Technology, University of California, Davis
Properties and Functions of Glutathione Peroxidase and Pentane Analysis of Lipid Peroxidation Damage to Quantitate Effects in Nutrition

43. Doctor T. Westermarck
Rinnekoti Institution for the Mentally Retarded, Espoo, Institute of Radiation Protection, Helsinki, Finland
Sodium Selenite Absorption and Losses in Spielmeyer-Sjogren Type of Neuronal Ceroid-lipofuscinosis (Batten's disease) Using Total Body Counting for 75 SE Detection
Studies on the Effects of Selenium Administration to Neuronal Ceroid-lipofuscinosis Patients with Special Refernce to Reduced Glutathione
Elemental Profiles of Blood Cells in NCL. Is Iron Involved in the Pathogenesis of NCL?

44. Doctor John R. Wherrett
Professor of Neurology Program, University of Toronto
Isolation of Fluorescent Material in the Juvenile Form of Batten's disease

45. Dr. H. M. Wisniewski
New York State Office of Mental Retardation and Developmental Disorders, Staten Island, NY
Lipofuscin in Aging

46. Doctor Leon Wolfe
Hopital Neurologique de Montreal, Montreal Neurological Hospital
Characterization of the Accumulated Retinal Compounds in Batten's disease

An Analysis of Urine Sediment in Subjects with Batten's disease
New Findings on Abnornmalities of Dolichol and Dolichol
Phosphates in Ceroid-lipofuscinoses and Relationships to
Lysosomal Membrane Turnover

47. Dr. C. E. Wright
New York State Office of Mental Retardation and Developmental
Disorders, Staten Island, NY
Altered Taurine Transport in Ceroid-lipofuscinosis

Senator HARKIN. I am curious as to why the NIH has ignored the language in the appropriation bill of last year. You say that $150,000 was spent directly on Batten disease in fiscal year 1987.

Dr. RIDER. Yes.

Senator HARKIN. Do you know how much is going on this year?

Dr. RIDER. About the same, I think.

Senator HARKIN. Can this disease be detected by amniocentesis?

Dr. RIDER. Yes; that was the latest thing in the last few years that has been developed.

The sad part is that children are normal to the age of 5, 6, or 7, and they start to deteriorate. So that you have 5 or 6 years in which you could do some effective treatment.

Senator HARKIN. Are there tests that you can take after a child is born to detect whether they have it?

Dr. RIDER. What was that?

Senator HARKIN. Are there tests that can be done to detect whether a child has Batten disease?

Dr. RIDER. There is a blood test, which our researchers are working on.

They have not done enough to be sure that they can come out and say that we can absolutely tell, but they are pretty confident that they can pick up carriers on those with the disease with this blood test. But they have to do many more to be sure.

Senator HARKIN. Thank you very much. We appreciate your testimony.

STATEMENT OF DR. JEROME C. GOLDSTEIN, EXECUTIVE VICE PRESIDENT, THE AMERICAN ACADEMY OF OTOLARYNGOLOGY-HEAD AND NECK SURGERY, INC.

Senator HARKIN. Next is Dr. Jerome Goldstein, executive vice president, American Academy of Otolaryngology.

Dr. GOLDSTEIN. Mr. Chairman, I am Dr. Jerome Goldstein, executive vice president of the American Academy of Otolaryngology-Head and Neck Surgery.

It is again my pleasure to appear before this subcommittee on behalf of the largest organization of otolaryngologists-head and neck surgeons in the world, with more than 8,000 members including 96 percent of all board certified otolaryngologists.

The NIH in their 1987 report to the Congress on hearing and communicative disorders estimates that more than 20 million Americans, nearly 10 percent of our population, suffer these communicative diseases.

Hearing losses particularly affect the elderly, with more than 50 percent over the age of 74 being affected. The NIH further concluded that "critical is the recruitment of qualified investigators. There is a profound lack of such expertise at present."

In my written testimony are the detailed remarks of Dr. Byron Bailey pertaining to the critical shortage of investigators in this field. The leadership of this academy has worked with NINCDS officials over the last year to design six new programs critical to the strengthening of our specialties research base, and more importantly the welfare of our patients.

These programs are for doctors in training and faculty and are described in detail. The lack of trained clinician scientists and the facilities in which such people can carry out their work must be corrected by both the profession and the NIH.

Our member physicians, through this academy, the Deafness Research Foundation, and other groups, now charitably provide more than $2.5 million a year to support research and research training for hearing and vestibular disorders.

We cannot do the job alone. There is a need for the NIH to provide expanded clinical research development opportunities which are specified for the study of hearing and vestibular disorders.

Such opportunities will help our physicians to develop the science and techniques needed to bring about the advances which are found in other areas of medicine. It will only be through this type of development program that the unmet needs of 20 million Americans with hearing and vestibular disorders will be satisfied.

The recent student demonstrations at Gallaudet University amplify the fact that the need of our Nation's deaf citizens have largely gone unmet. These deficits are being magnified by a rapidly aging population.

While there have been a few extraordinary advances such as the cochlear implant, this form of treatment for the profoundly deaf is costly and limited to a small number of patients.

In sum, our patients with hearing and vestibular disorders have not benefited to any great extent from progress in research. This must change. Our Nation's deaf community demands and justly deserves this help.

Before concluding my remarks, I feel it important to comment about your bill, Senator Harkin, S. 1727, that would establish a separate institute of the NIH for deafness and communicative disorders.

The academy enthusiastically supports this bill and really appreciates your interest and efforts in this endeavor. We know how hard you have worked.

PREPARED STATEMENT

The academy knows that once again the administration's budget proposal for the NINCDS in fiscal year 1989 is significantly less than opportunity demands. We enthusiastically support the NCR budget committee report which recommends the NINCDS receive $704.5 million for fiscal year 1989. Thank you very much for the opportunity to present this testimony.

[The statement follows:]

STATEMENT OF DR. JEROME C. GOLDSTEIN

Mr. Chairman and members of the Subcommittee, I am Dr. Jerome C. Goldstein, Executive Vice President of the American Academy of Otolaryngology-Head and Neck Surgery. It is again my pleasure to appear before this Subcommittee on behalf of the largest organization of otolaryngologists-head and neck surgeons in the world with more than 8,000 members, including 96% of all board certified otolaryngologists. I appreciate this opportunity to share the Academy's views regarding FY 1989 funding for the National Institutes of Health.

The National Institutes of Health (NIH), in their 1987 Report to the Congress on Hearing and Communicative Disorders, estimate that more than 20 million Americans, nearly 10% of our population, suffer from these diseases. Hearing losses particularly affect the elderly, with 30% of those aged 65 - 74 being affected, and more than 50% over the age of 74. The NIH also reported that no national data have been collected regarding voice and swallowing disorders in the elderly. Of course, these diseases do not only affect the elderly but all ages, races and demographic groups in our population.

The NIH further concluded that "critical to the expansion of this research endeavor is the recruitment of qualified investigators...there is a profound lack of such expertise at present." An editorial by Dr. Byron J. Bailey in the November 1987 issue of the American Academy of Otolaryngology-Head and Neck Surgery Bulletin echoed NIH's concerns. In his article, Dr. Bailey more fully outlined the scope and seriousness of this problem and offered possible solutions to increase the supply of trained clinical investigators in otolaryngology.

Specifically, Dr. Bailey noted that less than 1% of the physicians in our specialty are currently trained and funded for active, on-going clinical investigation. He also indicated that most of the funded clinical investigators are older, and fewer academicians in our specialty are being drawn toward an investigative career. Many factors have influenced this current situation, but a strategy must be developed and implemented to restore a strong cadre of trained clinical investigators. According to Dr. Bailey, we should strive to establish a "critical mass" of 200 well-trained and funded clinical investigators, or four times that of our current ranks.

The leadership of this Academy have worked with NINCDS officials over the last year to design six new programs critical to the strengthening of our specialty's research base and more importantly, the welfare of our patients. These programs are:

1. Resident Research Small Grant Awards - 25 grants of $10,000 should be made for a total cost of $250,000.

2. Fundamental Research Training Awards - 12 awards should be made at $30,000 - 40,000 each for an annual maximum cost of $480,000.

3. Advanced Resident Research Training Awards - Six awards should be made at a unit cost of $60,000 for a total annual cost of $360,000.

4. Research Training Award for Young Faculty - similar to the existing Career Investigative Development Awards (CIDA) but requiring evidence of a minimum of one prior year of research training.

5. Clinical Research Center Development Grants - funding 10 grants to support the development of centers capable of training investigators and conducting clinical research projects.

6. Institutional Clinical Investigators Development Awards - in otolaryngology designed as institutional versions of the present CIDA.

The lack of trained clinician scientists and the facilities in which such people can carry out their work must be corrected by both the profession and the NIH. The otolaryngologists through this Academy, the Deafness Research Foundation, American Otological Research Fund and other groups are now providing more than $2,500,000 a year to support both basic and applied research and research training for hearing and vestibular disorders. These resources are primarily going to young clinical investigators and are being used as initial grants to allow these recipients to develop into clinical scientists who can successfully compete in the NIH peer review process for further appropriate support. It must be noted that the academic departments of Otolaryngology are also contributing, through their own budgets, considerable funds to the development of scientific investigators.

The recent student demonstrations at Gallaudet University amplify the fact that the needs of our nation's deaf and communicatively impaired citizens have largely gone unmet. These deficits will soon be magnified by our rapidly aging population. While there have been a few extraordinary advances such as the cochlear implant, this form of treatment for the profoundly deaf is costly and limited to a small number of patients. In sum, our patients with hearing and vestibular disorders have not benefitted to any great extent from progress in research. This situation must change. It will be an expensive endeavor but one that our nation's deaf community will surely demand and justly deserve.

Otolaryngology cannot do the job alone. There is the need for the NIH, through the NINCDS, to provide expanded clinical research development opportunities which are specified for the study of hearing and vestibular disorders. Such opportunities will help our physicians to develop the science and techniques needed to bring about the advances in hearing and vestibular impairment which are found in other areas of medicine. It will only be through this type of development program that the unmet health needs of 22,000,000 Americans with hearing and vestibular disorders will be satisfied.

Before concluding my remarks, I feel it is important to comment about a bill, S.1727, which is rapidly moving forward that would establish a separate institute at the NIH for deafness and communication disorders. This legislation was accepted as an amendment to S.2222. the NIH Reauthorization Bill, and reported out of the Senate Labor and Human Resources Committee on April 13, 1988. It is not certain that this legislation will be passed in time for this appropriations cycle. The Academy would like to respectfully urge the Subcommittee to consider now to provide for the level of funding necessary to carry out the important research and training programs in hearing, balance, language, voice, chemosensory and related disorders at the proposed new institute, if established by law. We are aware that if this appropriations cycle is missed, there may be the possibility of providing funds through a supplemental appropriations bill later this year or early next year.

The Academy notes that once again the Administration's budget proposal of $557.5 million for the NINCDS in FY 1989 is significantly less than opportunity demands. We enthusiastically support the National Committee for Research Citizens Budget Committee report which recommends that the NINCDS receive $704.5 million for FY 1989. This level of funding is necessary to meet the requirements for the programs as outlined in the monograph on Decade of the Brain.

Thank you very much for the opportunity to present this testimony.

Senator HARKIN. Dr. Goldstein, thank you very much. Thank you for your support of the legislation. We hope we can get that through here this year.

There are roadblocks along the way but we have had those before. So I appreciate your being here. I appreciate your testimony. Thank you very much.

STATEMENT OF GERALDINE DIETZ FOX, CHAIRPERSON, GOVERNMENT RELATIONS COMMITTEE AND MEMBER OF THE BOARD OF DIRECTORS, DEAFNESS RESEARCH FOUNDATION

ACCOMPANIED BY:

LARRY BROWN, MEMBER, BOARD OF DIRECTORS, DEAFNESS RESEARCH FOUNDATION

RACHEL DUBIN, STUDENT, BALTIMORE, MD

LOUISE FLETCHER, MEMBER, BOARD OF DIRECTORS, DEAFNESS RESEARCH FOUNDATION

Senator HARKIN. Next I would like to call Geraldine Fox of the Deafness Research Foundation. I understand she will be accompanied by Larry Brown and Louise Fletcher. Please have a seat, and also, is this Rachel Dubin? I welcome you to the subcommittee.

Senator Specter wanted to be here to introduce you, but as you know he had a slight illness. He had an operation on his leg yesterday and is in the hospital. But I understand that he is OK.

I would like to introduce Geraldine Dietz Fox, member of the board of directors and chairperson of the Government Relations Committee of the Deafness Research Foundation.

The Deafness Research Foundation is a 30-year old private nonprofit organization dedicated to finding prevention, treatment, and cures of deafness and hearing disorders.

Ms. Fox has testified before this committee last year. She has lobbied on the Hill for several years and has increased public understanding of the needs of hearing-impaired individuals. The last year and a half she has been a strong proponent of the establishment of the separate National Institute on Deafness and Communication Disorders.

Also Larry Brown, who we have had here before, former member of Washington's favorite and only football team, the Redskins. He won the 1972 NFL player of year award. Mr. Brown is now the business community relations manager for the Xerox Corp.

Last year he testified with Ms. Fox before the House and Senate Appropriations Committees, and this year testified before Congressman Waxman's Health and Environment Subcommittee in favor of establishing the National Institute on Deafness and Communications Disorders. Mr. Brown is also a member of the board of directors of the Deafness Research Foundation.

I understand we also have Louise Fletcher, who as we know appeared in the movie, "One Flew Over the Cuckoo's Nest," which I remember very well. How many years ago was that?

Ms. FLETCHER. A few.

Senator HARKIN. Well, we do not want to talk about that.

Ms. FLETCHER. That is over 10 years ago.

Senator HARKIN. And do I understand that this is Rachel Dubin?

Ms. FLETCHER. Yes.

Senator **Harkin**. This is Rachel Dubin from Baltimore, MD, 11 years, in the sixth grade at Park School in Baltimore.

This unusual young lady, in spite of a profound hearing impairment, manages in a regular classroom with an auditory trainer. This instrument is used with her hearing aid and helps her to hear the teacher's voice without any background noise.

Her teachers all write on the board, and from this she takes her own notes. Rachel is quite independent, studying long hours to constantly improve her speech and listening capacity.

I personally want to thank all of you for being here. You all know of my intense interest in this area. We welcome you here, and please proceed. I will try to give you each 3 minutes.

Ms. Fox. Thank you, Mr. Chairman and members of the subcommittee, for the privilege of appearing before you today.

Last year when I testified for expanded deafness research funds within the National Institute of Neurological and Communicative Disorders and Stroke, I was extremely encouraged when the Senate, guided by the strong leadership of Senators Chiles, Weicker, and Harkin, wrote that they considered research on hearing problems to be of great importance and recommended that activity in this field be significantly expanded.

Apparently, within the current structure, this has not been possible. However, the inequities might change at last.

On April 13, 1988, under Chairman Senator Edward Kennedy and ranking minority member Senator Orrin Hatch, the Senate Labor and Human Resources Committee approved the establishment of the National Institute on Deafness and Other Communication Disorders as part of the National Institutes of Health reauthorization bill. This important legislation was introduced by Senator Tom Harkin and Congressman Claude Pepper in the House.

I want to especially recognize Senator Harkin and Senator Weicker of this committee for their foresight in approving and supporting legislation for a new Institute. Their faith in this endeavor has been a source of strength for all peoples afflicted with communication disorders.

Assuming that there would be an increase above the President's budget request of $571 million for fiscal year 1989, this would increase the NINCDS appropriations to $668 million.

Information that we have states that NINCDS recommends an operational budget of $703 million for fiscal year 1989 in order to achieve a funding level of 50 percent for approved grant applications. NINCDS has also stated that it allocates 20 percent of the total funds for the Communicative Disorders Program.

Therefore, the funding for the Communicative Disorders Program for fiscal year 1989 for research and research training would total $133.6 million. If the House takes similar action in approving the Institute in the next few weeks, and it creates the National Institute on Deafness and Other Communication Disorders, we would hope that at least the same amount of money will be provided by this committee for the new Institute, along with the necessary funds required for establishing administrative operations.

Please keep in mind that in the past the Senate has used strong language when recommending additional funds for deafness. But their words have gone unheeded.

Based on testimony over the past years, we critically need research centers and training programs. The Senate has given implicit directions to NINCDS while increasing their appropriations, but deafness and other communication disorders have not gotten their fair share of this increase.

To meet the critical present needs and to make up for past underfunding, please consider adding 10 percent more to this base figure of $133.6 million. Then we can start to prevent the rapidly increasing cost to our society from deafness, which has now been estimated at $30 billion annually.

We look forward to the day when deafness will no longer be the silent ignored disease, and Americans with hearing and other communication disorders will be productive participating citizens again.

Mr. Chairman and members of the subcommittee, each year we are allowed to come and inform you of the changes and needs of our concern, and in this way we are able to share important information with you.

We are deeply grateful to you and your fine legislative staff for your valuable time, interest, and consideration. Thank you for allowing me to express my thoughts to you.

[The statement follows:]

STATEMENT OF GERALDINE DIETZ FOX

I am Geraldine Dietz Fox, Chairperson of the Government Relations Committee of the Deafness Research Foundation, a 30-year-old, non-profit, volunteer organization dedicated to finding preventions, treatments and cures of hearing disorders.

Last year, I appeared before you to testify for expanded deafness research funds within the National Institute of Neurological and Communicative Disorders and Stroke. Many of us were delighted and grateful, especially to Senators Chiles, Weicker and Harkin, not only for their previous leadership, and present guidance, but for their strong Report Language. On September 25, 1987, the full Senate Appropriations Report concluded:

> ....Concerns have been expressed that not enough funds are being channeled by the NINCDS into deafness research to discover the cause, prevention, treatment, and cure of hearing and balance disorders.
>
> ....The Committee considered research on hearing problems to be of great importance because of the large number of older Americans who suffer various degrees of hearing loss. With the increased resources made available, and within the limits of the science opportunities currently available, the Committee strongly recommends that activity in this field be significantly expanded.
>
> ....The Committee directs that a strong, sustained effort, targeted on hearing disorders, would enable scientists to pursue some of the more promising areas of investigation....

Apparently, within the current structure, this has not been possible. Hearing, speech and language, balance, and sense disorders (taste and smell) are collectively known as Communicative Disorders. They comprise 60 percent of the disorders for which the entire Neurology Institute is responsible, yet, in 1987, these disorders received less than 14 percent of the total NINCDS budget. **Only 200 of the 2,357 grants awarded by the Neurology Institute were for hearing and balance, while the total Communicative Disorders Program received 320 grants.**

Let's compare the 1987 funding of some of the major diseases of both the Neurology and Communicative Disorders Program:

1. Alzheimer's Disease and Presbycusis (hearing in the aged) both have profound effects on the older citizen, causing withdrawal, isolation, and great reliance on social services.

   Alzheimer's Disease and related dementias affect 3 million Americans and received 39 grants for $17,776,000. Presbycusis, the third most chronic condition in persons 65 years and older, affects 4 million senior citizens now, and will affect 10 million by the year 2025. It received 4 full grants and 5 partial grants for $1,278,080.

2. Parkinson and Huntington Diseases, along with other movement disorders affect 500,000 people and received 58 grants for $15,625,000. Let's combine Congenital Deafness, which affects 1 in every 1,000 babies, and Otitis Media, a middle ear infection which can cause deafness and learning disabilities in the young child and affects 20 million children under the age of 3. Combined, they received 14 grants for $5,398,198.

3. May I point out that in 1987, the $34 million funding for Epilepsy, which affects only 2 million people, was equivalent to almost the entire amount of funding for Hearing and Vestibular Disorders, which affects 14 million people.

Another important part of the National Institutes of Health (NIH) is its Intramural program. In the Neurology Institute, there are 12 Laboratories and 9 branches involved in clinical and basic research. Only one of these 21 units is dedicated to Hearing.

Within the last 10 years, the Communicative Disorders field has grown dramatically in its strength and maturity. The number and quality of researchers have increased in competency. The high funding rates and priority scores that our scientists have received attests to both the quality and maturity of our science.

But there are good grants, good scientists, and good laboratories that have been approved, but which have not been funded because the resources were not judiciously allocated. This, coupled with the priorities of the Neurology Institute, has made it almost impossible to focus on the many problems that need solutions.

While this is especially acute in the Communicative Disorders field

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because of its historic lack of support, it is not unique. More funds for Basic Bio-medical Rresearch must be a priority for this nation.

We can only hope that, soon, interest and research in hearing and communicative disorders will become as important as another sensory disorder, the eye.

A booklet from the Eye Institute shows 17 clinical trials are now in progress on such important projects as laser therapy for diabetic eye diseases and glaucoma. The Communicative Disorders Program can only point to 3 similar types of studies: one on Cochlear Implants; and two dealing with Otitis Media, the most common disorder in young children for which medical attention is sought. There is no reason to believe that we cannot make as great strides in the treatment of ear diseases as eye researchers have made in solving vision problems. We simply need the opportunity to do so.

In 1987, $80,000,000 was spent on 320 grants for the total Communicative Disorders Program serving 28 million people; while the Eye Disorders Program spent $216,528,000 on 1,317 grants which serve 1.7 million visually impaired persons and 500,000 legally blind persons.

This year, though, we have been encouraged that the inequities might change at last. On April 13, 1988, under the leadership of Chairman Senator Edward M. Kennedy and Ranking Minority Member Senator Orrin G. Hatch, the Senate Labor and Human Resources Committee approved the establishment of the National Institute on Deafness and Other Communication Disorders as part of the National Institutes of Health Reauthorization Bill. This important legislation was introduced by Senator Tom Harkin and Congressman Claude Pepper in the House.

I want particularly to recognize Senator Harkin and Senator Weicker, of this Committee, for their foresight in approving and supporting legislation for a new Institute. Their faith in this endeavor has been a source of strength for all peoples afflicted with deafness and other communication disorders.

Assuming that there would be an increase above the President's Budget Request of $571 million for NINCDS for FY '89, this would increase the NINCDS Appropriations to $668 million. (Information that we have, states that NINCDS recommends an operational budget of $703 million for FY '89, in order to achieve a funding level of 50% for approved grant applications.) NINCDS has also stated that it allocates 20% of the total NINCDS funds to the Communicative Disorders Program. **Therefore, the funding to the Communicative Disorders Program for FY '89, for research and research training, would total $133.6 million.**

If the House takes similar action in approving the Institute in the next few weeks, and creates the National Institute on Deafness and Other Communication Disorders, **we would hope that, at least, the same amount of money would be provided by this Committee for the new Institute, along with the necessary funds required for establishing administrative operations.**

Please keep in mind that, in the past, the Senate has used strong language when recommending additional funds for Deafness and Other Communication Disorders, but their words have gone unheeded. Based on testimony over the past years, that we critically need Research, Centers, and Training Programs, the Senate has given implicit directions to NINCDS while increasing their Appropriations; but Deafness and Other Communication Disorders have not gotten their fair share of this increase.

To meet the critical present needs, and to make up for past underfunding, please consider adding 10% more to this base figure of $133.6 million. Then we can start to prevent the rapidly increasing cost to our society from deafness, which has now been estimated at $30 billion annually.

We look forward to the day when deafness will no longer be the silent, ignored disease, and 28 million Americans with hearing and other communication disorders will be productive, participating citizens again.

Mr. Chairman and members of the Subcommittee, each year we are allowed to come and inform you of the changes and needs of our concerns and, in this way, we are able to share important information with you.

We are deeply grateful to you and your fine legislative staff for your valuable time, interest and consideration.

Thank you for allowing me to express my thoughts to you.

NINCDS GRANT ALLOCATIONS
for some of the Communicative Disorders

1987 ALLOCATIONS *

Disorder	#People	# Grants**	$ Allocation
Otitis Media with Effusion in Children	15-20% of all Children		
Active Chronic Otitis Media	4-6 Million		
Healed Otitis Media with Sequellae	20 Million		
		10**	$5,076,953
Tinnitus	17% of the Population (@ 34 Million) with Mild Disturbance 1% of the Population (@2 Million) Suffer Severe Problems 1/2% of the Population (1 Million) are Unable to Lead Normal Lives	3	$ 240,354
Sudden Deafness	20,000 New Cases per year	2	$ 316,470
Stuttering	0.46% of the Population (@920,000)	No Single Grant, but 10% of ea. of 3 grts.	$ 194,345
Congenital Deafness	1 in every 1,000 Babies	4	$ 321,245
Presbycusis	3rd most common Chronic Cond. in persons 65 yrs. or older (@ 284 per 1,000 persons)	10**	$1,278,080

* Information provided by **Legislative Analysis Branch**

** Whole and Partial Grants

NINCDS GRANT ALLOCATIONS
for some of the Neurological Diseases

1987 ALLOCATIONS *

Disorder	# People	# Grants	$ Allocation
Stroke	1,900,000	121	$32,909,000
Epilepsy	2,000,000	162	$33,663,000
Alzheimer Disease & related dementia	3,000,000	39	$17,776,000
Parkinson Disease,		43	
Huntington Disease,		15	
& other Movement Disorders	500,000		$15,625,000
Multiple Sclerosis	131,000	138	$33,707,000
Amyotrophic Lateral Sclerosis	14,000	35	

* Information provided by: Legislative Analysis Branch

ANNUAL COSTS TO SOCIETY OF HEARING,SPEECH, AND LANGUAGE DISORDERS *

1987

Disorder	Cost to Society **
Deafness	$ 1.8 Billion
Partial Deafness	$11.6 Billion
Speech	$ 9.00 Billion
Language	$ 7.53 Billion
TOTAL	**$29.93 BILLION**

* **NINCDS: PROFILE; November 1987**

** Cost of Health Care, the added Cost of Special Education Programs, and Loss of Income due to illness

WHAT CAN WE FORESEE IN THE FUTURE? WHERE COULD DEAFNESS RESEARCH BE IN 10-20 YEARS WITH INCREASED FUNDING?

A) Application of space-age technology promises better hearing aids to improve understanding of speech for the majority of those affected and....

Surgically implantable hearing aids with sufficient clarity to assist those for whom prevention fails. Also,....

Critical need to study the effects of cochlear implants in children.

B) Indentification of genes which cause deafness. This would address the question of why children are born deaf or why people experience sudden hearing loss.

C) It is possible to grow the inner ear machanism in tissue culture; what if such bold research could lead to the replacement of damaged inner ear sensory cells?

D) Development of a vaccine for Otitis Media with accompanying clinical trials. Also, determining effectiveness of drugs to alleviate tinnitus, Meniere's Disease, noise induced hearing loss, and hearing in the aged, with accompanying clinical trials.

E) Increased knowledge of how sound received by the ear is transmitted to the brain. Important for diagnosing and treating yound children, who do not develop language, and elderly people who cannot understand the words that they hear.

F) Development of reliable and valid measures of the hearing of children under two years of age because of the critical necessity for setting accurate levels on hearing aids for hearing-impaired youngsters.

By accelerating and facilitating research into the preventions, causes, diagnosis, treatments, and cures of all the communicative disorders, you can positively affect the quality of life for many of us here today.

Senator HARKIN. Thank you very much, Ms. Fox, for your continuing support and interest in this. You have provided a lot of information that we can use.

Let me get one thing clear. You are asking for funding for the communicative disorders program, $133.6 million?

Ms. FOX. $133.6 million is what they should receive in fiscal year 1989 from NINCDS.

Senator HARKIN. But in 1987 you said they received for deafness and communicative disorders about $80 million which was spent on 320 grants.

Ms. FOX. Well, I am going by the figures that the last few years the Congress has increased the President's budget by 17 percent, plus the 20 percent of that budget that NINCDS gives to us.

Senator HARKIN. Thank you very much. Mr. Brown, welcome again to the subcommittee. Do I have a statement from you? Yes I do, I have a statement. Please proceed.

STATEMENT OF LARRY BROWN

Mr. BROWN. Thank you. Mr. Chairman, members of the appropriations subcommittee, I appreciate the opportunity to testify before you today.

Deafness has been called the invisible impairment. Like 28 million other Americans, my own deafness is not noticed until I fail to respond to a greeting, or miss the point of a joke.

When I was growing up, it was obvious when a friend had a visual impairment he or she wore glasses. But my deafness was never acknowledged until later. And often I tried to hide it.

The protest this year over the selection of a president at Gallaudet University demonstrates that deaf people want to be heard and actively involved in decisions that affect their lives.

In a world where power means getting heard, powerlessness has long been the status quo for the deaf. A separate Institute will provide us with a home of our own. We need to help control our destiny.

Just as the right blend of talent, resources, and management makes a football team or a corporation powerful and successful, the same principle is true if you bring doctors, scientists, and technicians together to find solutions to our country's most chronic impairment.

PREPARED STATEMENT

This committee has already been generous with its vocal support. Now it is time to reinforce this support with the kind of funding that will make this dream a reality. Thank you very much.

[The statement follows:]

STATEMENT OF LARRY BROWN

Mr. Chairman, Members of the Appropriations Subcommittee. I appreciate the opportunity to testify before you today.

Deafness has been called "The Invisible Impairment." Like 28 million other Americans, my own deafness isn't noticed until I fail to respond to a greeting or miss the point of a joke, so sometimes you feel left out.

When I was growing up, it was obvious when a friend had a visual impairment - He wore glasses - But my deafness was never acknowledged until later, and often, I tried to hide it.

The protests this year over the selection of a President at Gallaudet University demonstrate that deaf people want to be heard and actively involved in decisions that affect their lives. In a world where power means getting heard, powerlessness has long been the status quo for the deaf.

That's why the hearing impaired community was so pleased when Congressman Claude Pepper and Senator Tom Harkin introduced a Bill to establish a National Institute on Deafness and Communication Disorders. We were even more excited when the Senate (Labor and Human Resources) Committee **approved** the establishment of this separate Institute, as an amendment to the NIH Reauthorization Bill.

Just as the right blend of talent, resources, and management makes a football team, or a corporation, powerful and successful, the same principle is true if you bring doctors, scientists, and technicians together to find solutions to our country's most chronic impairment. Thank you.

Senator **Harkin**. Mr. Brown, thank you very much for being here, and your continued support in this area. I appreciate it very much. I know the entire committee does also.

Ms. Fletcher, welcome to the subcommittee.

STATEMENT OF LOUISE FLETCHER

Ms. **Fletcher**. Thank you very much, Mr. Chairman, members of the committee. Thank you for the privilege of speaking to you today.

I am the daughter of deaf parents, and a member of the board of the Deafness Research Foundation, and I have an enduring and passionate interest in all things affecting the deaf. And I try to do whatever I can to help out, and being here today is one of those things.

I do not have a prepared statement, but I would just like to relate something to you. The summer I was 10 years old I spent the entire summer climbing a tree, the tallest tree in our block.

I did not like climbing trees, but I thought that getting up to the top of this tree would put me closer to God, and maybe He could hear my prayer better than he heard my everyday ordinary bedtime prayers.

And my prayer was, please fix it so my mother and father can hear. You know, they need to hear the baby crying, they need to hear the doorbell and the telephone and the fire engine, and they needed to drive the car and they needed to talk to people and understand what they say when they are talking back to them.

They do not need a 10-year old to explain everything to them that is on the news, because I had an impossible time understanding the news, and I could not really explain it to them at 10.

So this came home to me when I was asked to come here and give my support for the establishment of this new Institute. And in the establishment of this new Institute, I believe that some of these prayers, like the one that I had when I was 10, would begin to be answered, about 28 million of them. And I thank you very much for letting me come today. That is my statement.

Senator **Harkin**. Well, thank you very much. I can appreciate that story and am able to somewhat relate to it.

Ms. **Fletcher**. I know.

Senator **Harkin**. But you are very kind, and I am honored that you are here to support this.

Rachel Dubin is here. Now, I do not know, Rachel, can you hear me? Or do you understand sign language? Can you read my lips?

STATEMENT OF RACHEL DUBIN

Ms. **Dubin**. Yes, Senator Harkin. Hello. My name is Rachel Dubin. I work very hard at speech, studying five times a week to learn to listen and get the most out of my hearing aid.

I do not sign but I am able to understand, with the use of my hearing aid and lip reading. The hardest parts of being hearing impaired are paying attention, not being able to hear what my friends are saying, and not hearing over the phone.

Sometimes my friends get frustrated when I ask them three times what they said. Often, they just give up trying to communicate with me and say, never mind.

I think that if the Government gave more money for deafness research they could develop better hearing aids and listening devices and determine why children lose their hearing without any reason, like I did.

Mr. Chairman, when I was little, I used to ask my parents questions like, when will I hear like other kids? And, what does a bird sound like? Now I ask more serious questions. Do you think I will ever be able to hear my friends' voices on the telephone? And, will my children be hearing impaired?

Please help me and other hearing impaired kids look forward to a better and brighter future. Thank you, Senator Harkin, for allowing me to speak to you today.

Senator **Harkin**. Well, thank you very much, Rachel.

Ms. **Dubin**. You are welcome.

Senator **Harkin**. We are honored to have you here. Are your parents here? Oh, these are your parents.

Well, we are very proud of you also. Do you know who we had before my subcommittee about a month ago? We had the actress Marlee Matlin who, as you know, also recently won an Academy Award, and I just want you to know that I see a lot of the same traits in you that I see in her.

Regardless of what setbacks you have had because of your hearing impairment, I think you have a very bright future in front of you. I think you are going to be very successful.

Ms. **Dubin**. Thank you very much, Senator Harkin.

Senator **Harkin**. Well, thank you. Now, tell me, Rachel, how do you understand what your teachers are saying in school, when your teachers are at the blackboard? Because sometimes teachers do not speak directly to you, and if you cannot see their lips——

Ms. **Dubin**. At first, they write on the board and then they start speaking. And also I use an auditory trainer. It is a machine that is removable, that attaches to my hearing aid. And my teacher has a microphone with battery packs. And it amplifies the teacher's voice and helps me to pay attention.

Senator **Harkin**. Thank you all very much. Do you have any questions?

Mrs. **Dubin**. We are hoping you will support our deafness research so that the things will improve in the future for our children communication-wise.

We think it is very important that she and other hearing impaired be very much a part of the hearing world society. Thank you for letting us speak today.

Senator **Harkin**. Well, thank you all for being here. You are all wonderful. And I appreciate all of your continued interest and support of this effort. Thank you all.

Ms. **Dubin**. Thank you.

Senator **Harkin**. Next will be Raymond Connors, president, American Tuberous Sclerosis Association. I am learning a lot of things here today. Mr. Raymond Connors? Mr. Raymond Connors, going once, going twice.

STATEMENT OF JOE A. PISCOPO, TREASURER, AMERICAN NARCOLEPSY ASSOCIATION, INC.

Senator **Harkin**. Next, Joe Piscopo, treasurer of the American Narcolepsy Association. I have not seen you on "Saturday Night Live."

Mr. **Piscopo**. No, sir; that is the other guy.

Senator **Harkin**. Mr. Piscopo, welcome to the subcommittee. Please proceed.

Mr. **Piscopo**. Thank you, Mr. Chairman. I am very pleased to appear before you today to present testimony concerning Federal efforts in narcolepsy research.

I am currently the treasurer and the director of the American Narcolepsy Association, a nonprofit organization established in 1975 for persons afflicted with narcolepsy. Our mission is to improve the quality of life for everyone who has narcolepsy, and our long-range goals will be achieved only when effective treatments are discovered and remain generally available to the narcolepsy patients of the world.

Mr. Chairman, I have narcolepsy. My condition was first diagnosed in 1965 at the age of 20. Narcolepsy is a sleep disorder that is characterized by inappropriate daytime sleepiness and disrupted nighttime sleep.

Narcolepsy is a lifelong illness. There is no known cure. It is estimated that more than 200,000 Americans suffer from narcolepsy, making it more prevalent than muscular dystrophy, hemophilia, and sickle cell disease.

For narcoleptics like me, excessive daytime sleeping occurs every single day of our lives, regardless of the amount of sleep we have had the night before.

To illustrate the effects of narcolepsy, I was involved in 15 automobile accidents between the ages of 16 and 20 that were the result of my falling asleep while driving. I was plain lucky to survive several of them that totally destroyed the cars I was driving.

Another example. In my 4-year college career, I actually slept through almost every class I attended, even the ones I liked a lot. I was obviously lucky to graduate from college at all. Most people with narcolepsy do not.

The social complications that accompany narcolepsy are much more than minor inconveniences or embarrassments. Attacks of daytime sleepiness often occur at very inappropriate times, in the classroom, at business meetings, during a meal, or even during conversation.

Learning and job performance can be severely hampered for children and adults, because the ability read, study, and concentrate are impaired. Parents, teachers, spouses, and employers frequently mistake the narcoleptic sleepiness for lack of interest or misconstrue it as a sign of hostility, rejection, or laziness.

Narcolepsy research is conducted through the National Institute of Neurological and Communicative Disorders and Stroke and the National Institute on Mental Health.

Mr. Chairman, the few narcolepsy studies that are now being conducted within NINCDS are very important. But clearly a greater Federal focus must be placed on narcolepsy research.

I have personally funded more narcolepsy research over the last 3 years than the National Institutes of Health, a total of almost $2 million. It is just not enough. A disorder that affects more than 200,000 people in such a serious way should be the object of a higher level of Federal funding for research.

We also recommend a separate and distinct program be established for directing and coordinating all narcolepsy research within the National Institutes of Health. A separate branch or agency for narcolepsy would establish specific responsibility for narcolepsy research within NIH.

PREPARED STATEMENT

That would promote individual accountability and initiative for narcolepsy research, and enhance cooperation between the National Institutes of Health and the private citizens who are concerned or are affected with narcolepsy.

Mr. Chairman, thanks for the opportunity to present this important testimony in support of a higher of funding for narcolepsy research.

[The statement follows:]

STATEMENT OF JOE A. PISCOPO

Mr. Chairman and Members of the Subcommittee, I am very pleased to appear before you today to discuss federal research efforts targeted toward narcolepsy.

The American Narcolepsy Association (ANA) is an independent, non-profit organization established in 1975 by persons afflicted with narcolepsy. I am a Direcotr of the American Narcolepsy Association and I have narcolepsy, as does Bill Baird, our Executive Director, who is accompanying me today. Our mission is to improve the quality of life for everyone who has narcolepsy, and members of their families.

Narcolepsy is a sleep disorder that is characterized by excessive daytime sleepiness, cataplexy (loss of muscle tone), hallucinations, sleep paralysis, and disrupted nighttime sleep. Narcolepsy is a lifelong illness. There is no known cure, and no report of lasting remission has been confirmed. It is estimated that more than 200,000 Americans suffer from narcolepsy, making it more prevalent than Muscular Dystrophy, Hemophelia, and Sickle Cell Disease. I am able to speak with you today only because of the medication that I am taking. Without treatment I might fall asleep right here and now or, more realistically, I would risk arriving here and being too sleepy to effectively present this testimony.

Among narcoleptics, excessive daytime sleepiness occurs every day regardless of the amount of sleep obtained at night. This is usually experienced as a heightened sensitivity (many times irresistibly) to becoming sleepy or falling asleep, especially in sleep inducing situations. Sometimes sleepiness occurs so suddenly and with such overwhelming power that it is referred to as a sleep attack. Some narcoleptic patients have several "attacks" each day.

Cataplexy is an abrupt loss of voluntary muscle tone, usually triggered by any number of normal emotions. Attacks can range in severity from a brief sensation of weakness to total physical collapse lasting several minutes.

Hallucinations are intense, vivid, sometimes accompanied by frightening auditory, visual, and tactile sensations, and occur upon awakening or falling asleep. These hallucinations are very difficult to distinguish from reality.

The social complications that accompany narcolepsy are much more than just minor inconveniences or embarrassments. Excessive daytime sleepiness often occurs at inappropriate times -- in the classroom, at business meetings, during a Congressional hearing, during a meal, or even during conversation. Learning and job performance can be hampered for children and adults because the ability to read, study and concentrate are periodically (or in some cases continuously) impaired. Parents, teachers, spouses, and employers often mistake the patient's sleepiness for lack of interest, or misconstrue it as a sign of hostility, rejection, or laziness.

Generally, a person suffers the debilitating affects of narcolepsy for 10-15 years before this disorder is correctly diagnosed. A combination of reasons for this include that patients do not suspect a medical problem until the symptoms become quite severe. Also, many physicians misdiagnose narcolepsy as some other disorder such as depression, or mistake cataplectic attacks for epilepsy (even though narcolepsy is not a form of epilepsy and requires different treatment).

Narcolepsy Research

Through the NIH, the National Institute of Neurological, Communicative Disorders and Stroke (NINCDS) specifically, and the National Institute on Mental Health at ADAMHA, narcolepsy research is conducted. Among the items being studied are the brain chemical acetylcholine. This chemical regulates rapid eye movement (REM) sleep, the state of our sleep that is associated with dreaming. Natural bodily events that take place during normal REM sleep parallel narcolepsy symptoms: the body becomes immobile, muscle tone decreases, and dreaming similar to hallucinations occurs. A narcoleptic sleep attack is in fact an inappropriate appearance of REM sleep. Studies are being conducted to determine how, or if acetylcholine is altered in narcolepsy. Mr. Chairman, the few studies that are being conducted within NINCDS are very important, but clearly an accelerated federal focus must be placed on narcolepsy research. During each of the last 3 years the American Narcolepsy Association announced the availability of research funding for narcolepsy, and each year received over 30 requests for approximately $3 million. Unfortunately, only $200,000 was available. I personally, Mr. Chairman, have funded more narcolepsy research than has NIH over the past 3 years. The magnitude of a disorder that affects more than 200,000 people in such a serious way should be the object of an increased level of Federal funding.

Further, within the scientific configuration of NINCDS, narcolepsy is housed within the Epilepsy Branch. For many years, because both epileptic patients and narcoleptic patients displayed paroxysmal symptoms, many believed a link existed between epilepsy and narcolepsy. Now it is generally agreed within the scientific community that the physiologic basis of narcolepsy is quite distinct from that of epilepsy, and treatment techniques are vastly different. We would like to recommend that a distinct program for narcolepsy research be established within the Convulsive, Developmental, and Neuromuscular Disorders program.

The American Narcolepsy Association supports an overall funding level of $8.5 billion for NIH, in accordance with the Ad Hoc Group for Medical Research Funding.

Mr. Chairman, thank you for the opportunity to present this important testimony. I am very pleased to respond to any questions you may have, and we look forward to working with your Subcommittee to enact a good bill.

Senator HARKIN. Mr. Piscopo, thank you very much for your testimony.

Before you leave, they tell me that narcolepsy is housed within the epilepsy branch.

Mr. PISCOPO. Yes; it is.

Senator HARKIN. Where should it be?

Mr. PISCOPO. If anywhere, it should be a separate branch by itself. It is quite unrelated to epilepsy.

I am not a doctor, but medically and physically, symptomatically and clinically, it is an entirely distinct and separate ailment.

It is a neurological disorder, and I think there is an effort being made, a lobbying effort being made on the association of sleep disorder centers as well as the American Narcolepsy Association supports a separate sleep disorder institute or branch or agency within the NINCDS.

Senator HARKIN. You were saying that each year for the last 3 years the association received over 30 requests for approximately $3 million?

Mr. PISCOPO. Yes.

Senator HARKIN. But only $200,000 was available?

Mr. PISCOPO. That is correct.

Senator HARKIN. Was that from your association or NIH?

Mr. PISCOPO. That is from me personally.

Senator HARKIN. How much has NIH been putting into this?

Mr. PISCOPO. I believe the figure is approximately just under or just over $1 million a year. It is not very much.

Senator HARKIN. And you are asking for at least $8.5 million, is that what you are saying?

Mr. PISCOPO. No, sir; $8.5 million, I think, was——

Senator HARKIN. Oh, for NIH in total.

Mr. PISCOPO. I think the basic research grants for narcolepsy specifically should be increased by anywhere starting at about 25 percent or more.

Senator HARKIN. What kind of medicine do you take for narcolepsy?

Mr. PISCOPO. I take a stimulant which is an amphetamine-type drug called desoxyn, d-e-s-o-x-y-n.

Senator HARKIN. And it is a lifelong illness, no known cure.

Mr. PISCOPO. That is correct. I take 100 milligrams every morning without exception. And I have since 1969.

Senator HARKIN. That is tough.

Mr. PISCOPO. It is expensive too.

Senator HARKIN. And there is probably a lot of misdiagnosis going on?

Mr. PISCOPO. Oh, yes. I was fortunate. I was correctly diagnosed my first time around, although it was late. I had already slept through college and had a lot of automobile accidents.

Many misdiagnoses occur because there is not a lot of treatment in medical schools. People have gone through a lot of problems as children growing up, learning disabilities, and complications getting jobs and keeping jobs.

Senator HARKIN. Well, Mr. Piscopo, thank you very much for bringing this to our attention.

Mr. PISCOPO. You are very welcome, Senator. Thanks for the opportunity.

STATEMENT OF DR. ARTHUR FALEK, DIRECTOR, HUMAN AND BEHAVIORAL GENETICS RESEARCH LABORATORY, EMORY UNIVERSITY SCHOOL OF MEDICINE

Senator HARKIN. Next is Dr. Arthur Falek from the Emory University School of Medicine, testifying on behalf of funding, I believe, for Huntington's disease. Dr. Falek, welcome to the subcommittee. Please proceed.

Dr. FALEK. Before I talk about Huntington's disease, I just wanted to tell you that you have provided an education for me this morning.

When I was a young scientist at Columbia University, we started a brand new research program in genetics of deafness. And at that point, it was 1957, 1958, we, the National Institutes, were suggesting that there were several thousand deaf people in the United States. And we found more than the number that the National Institutes had suggested for the United States in the State of New York.

So it is a remarkable educational experience that I have had here this morning just listening. Thank you.

Senator HARKIN. Well, thank you, Dr. Falek.

Dr. FALEK. I have brought with me today, Senator, Mr. and Mrs. William Stowers of Vienna, VA, and Nancy Logan of the Washington chapter of the Huntington's Disease Society.

Mr. Stowers has been diagnosed with Huntington's disease since 1981, and he shows evidence of the neurological as well as some of the psychiatric features of this disorder, which are progressive through the 15- to 20-years survival after onset usually, which is usually in the mid-thirties to early forties.

The progressive nature of this inherited disease requires nursing home or institutional care of some sort midway through the illness.

I want to thank you and ask you to continue your recent actions in support of the catastrophic illness legislation, which include the first steps in protecting the spouses of affected individuals and the loss of life savings to pay for the long-term nursing home or other institutional care services.

There are over 25,000 individuals affected with Huntington's disease, and more than 125,000 at-risk relatives who have a 50-percent chance of developing this disorder.

In the few moments of time still allotted to me, I am pleased to inform you that in addition to the steady progress in specifically locating and sequencing the gene for Huntington's disease at the molecular level, the mechanism underlying the death of specific brain cells resulting in progression of this disorder are also being investigated.

An animal model has now provided evidence that the destruction of a particular class of a neuroexcitatory glutamate receptor N-methyl-D-aspartate produces a cascade of events which results in the selective death of the spiny neurons of the basal ganglion.

Furthermore, there is initial evidence that the apparent mechanism underlying this selective neuronal death has been uncovered and that the receptor antagonist MK-801 can reverse this occurrence.

In animal studies, the destruction of the spiny neurons is completely blocked when MK-801 is given systematically. It is important to point out that N-methyl-D-aspartate antagonists like MK-801 has in addition potent anticonvulsant properties, are also muscle relaxants, and appear to act as behavioral stimulants.

PREPARED STATEMENT

Your support for basic research in Huntington's disease, therefore, helps to gain understanding about the causes and mechanism underlying this disease, and also furthers understanding about the causes and mechanisms of other genetic and neurological disorders. Thank you.

[The statement follows:]

STATEMENT OF DR. ARTHUR FALEK

Thank you for the opportunity to appear before you as Chairperson of the Research Committee of the Board of Directors of the Huntington's Disease Society of America. Huntington's Disease (HD) is a dominantly inherited neurological and psychiatric disorder which has a chronic degenerative course lasting 15-20 years. The mean age of onset is from the 30's through the early 40's with a range from age 4 through the late 60's. Each child of an affected parent has a 50 percent chance of developing this illness. Symptoms include loss of control of voluntary movements, psychological changes such as depression and irritability as well as progressive dementia. As the disease progresses, home care may become impossible due to the patient's continuous, random involuntary movements and deteriorating mental state. In some cases, the patient may become agitated, violent and destructive of others as a result of neuronal cell loss. The cause of death is typically aspiration and pneumonia along with malnutrition despite increasing food consumption.

Molecular genetic techniques have identified markers close to the HD gene and enhanced information for genetic counseling to immediate relatives of affected individuals. While this is a very positive step, methods for preclinical control of disease progression in gene carriers as

It is estimated that there are 25,000 individuals affected with HD and 125,000 first degree at-risk relatives now living in the United States. The occurrence of this illness in one member devastates the entire family. The loss of income, the long course of the disease and the need for professional patient care, especially in later stages of the illness, combine to obliterate any semblance of achieved economic independence. Though some HD patients remain at home until their deaths, the majority are eventually placed in nursing homes or state institutions. Those who remain at home initially receive adequate care through a family networking effort which in time exhausts the participants both emotionally and financially. Support for the networking effort can be supplemented to some degree by state sponsored programs which are feasible into the intermediate stage of nursing care but less so as the disease reaches the later stages when skilled nursing is required. As noted in an Administration Report to the Secretary of Health and Human Services about Private Financing of

Long Term Care for the Elderly, the presence of mental deterioration (dementia) decreases the ability of an individual to cope with a physical disability and thus increases the likelihood of a need for nursing home placement. In fact, dementia accounts for the largest percentage of long-stay nursing home residents.

Financial options to fund intermediate or skilled nursing care are limited. For middle income families the Catastrophic Illness Bill now in Congressional Conference may be helpful in very short term (up to 150 days) for HD families as it will only provide a short respite for a disorder that may require nursing home care for at least a decade. On the average, the yearly cost for such care is at a minimum of $22,000-25,000 per year.

The typical picture for an HD family attempting to care for an affected member is that private insurance and Medicare benefits are exhausted first, then personal assets are rapidly depleted to the point of impoverishment for both spouses and only then can Medicaid be called upon to sponsor the remainder of the individual's long-term care.

For adequate long-term care of HD patients, a multifaceted approach is needed which should be a marriage of creative private and public financing efforts. In the private sector three broad options should be expanded: risk pooling through long-term insurance, cash accumulation and resource mobilization through tax credits. Of these, the most feasible appears to be development of increasing options for longer term nursing home insurance possibly combined with continuing care retirement communities or Social Health Maintenance Organizations (SHMO) and financed by an Independent Medical Account (similar to an IRA) or a Home Equity Conversion. While such strategies would assist middle and upper income families, they would remain out of reach for the majority of HD families.

Possibilities for assistance to families who are caregivers are to expand tax advantages under the Child and Dependent Care Tax Credit so that caregivers can claim a deduction for care of their dependent, disabled relative. In a similar vein, the definition of family dependents should be expanded to include those who do not live in the home of the care provider, the lower limit to obtain a tax deduction by the caregivers should be reduced and the age requirement of the dependent patient for nursing home and other health benefits in the bills now before Congress should be lowered. To further support family caregivers, a social security drop-out credit should be provided to remove the years of unemployment during the time of care for the disabled relative when the caregiver applies for his/her own social security benefits.

Current legislation which addresses some of these issues covering aspects of both private and public options are the Catastrophic Illness Bill mentioned earlier, the Long-Term Home Health Care Bill and the Lifecare proposal. The Huntington's Disease Society of American is pleased to learn that the Catastrophic Illness Bill has passed both houses of Congress and is now in Conference Committee.

An aspect of this bill that is of special significance to HD families is the Spousal Impoverishment Amendment proposed by Representative Barbara Mikulski. Other aspects of this bill of benefit to HD families are extension of Medicare to cover 80 hours of respite care, financing of research on long-term services particularly Adult Day Care Centers, extension of the four Social Health Maintenance Organizations (SHMO) until 1992, case management programs for Medicare beneficiaries with catastrophic illness and establishment of a commission to study comprehensive health care. We should like to give this bill and the identified provisions our strong support.

The Home Health Care Bill would complement the Catastrophic Illness Bill by approving Medicare coverage of home health care which so many disabled and elderly people prefer to nursing home placement or institutionalization. Studies have found this approach to be cost effective.

A comprehensive health care proposal such as that reported from Senator Kennedy's office, the Lifecare Bill, appears to address the medical needs of HD patients and their families but is still in development.

While all of these efforts will assist HD families in a variety of ways, they will not facilitate long-term nursing home care for their affected relatives who, similar to Alzheimer Disease (AD) patients, present management problems to the extent that they are frequently rejected by private care facilities. Those with HD, as a rule, survive many more years than patients with AD and in addition to continuously exhibiting random, uncontrolled movements (most disturbing to care-facility personnel) some strike out aggressively when irritated. What is essential are long-term care facilities for such patients no matter when the age of onset. Several states are devloping such programs (New Jersey, Massachusetts), but a national effort is required to provide for such facilities throughout the United States.

Congressional help is therefore, requested to advance both the biomedical and the health care programs for HD patients and their families. The immediate aim is to enhance the quality of life for family members as well as the victims of this tragic disease that spans almost a generation of time from its onset to the patient's death. The longer term goal is to develop pharmacologic measures to treat and possibly prevent the onset of HD based on knowledge obtained through molecular biology investigations about the aberrant product(s) of the mutant gene.

These goals can be reached with continuing Congressional support to intensely study this prototype of a late onset, long-term debilitating genetic disorder.

Senator HARKIN. Thank you very much, Dr. Falek. It is amazing. I have heard a lot about Huntington's disease. But I have never been aware of what Huntington's disease was and how it affects people.

Dr. FALEK. That is why I thought it would be important for someone who is supporting research in the area to see something about what a patient appears like.

Senator HARKIN. Now, the patient you have with you——

Dr. FALEK. William Stowers.

Senator HARKIN. And when was he first diagnosed?

Dr. FALEK. 1981. That does not mean that that was when he developed the disease. That was when he was brought to the neurologist and was diagnosed, so the disease had progressed to the point of diagnosis.

Senator HARKIN. I see. Is this Mrs. Stowers?

Mrs. STOWERS. Yes.

Senator HARKIN. Can you relate to me what it was that first brought him to the attention of the doctors?

Mrs. STOWERS. He had shakes, just a slight shake, a tremor, and he drove a tanker at the time for Gulf Oil. And I kind of thought it was just nerves because that is a very nerve-wracking business.

But it just got worse, and one of his aunts came to me and she said, I think he has Huntington's. His mother had it. And I did not know that when we were married. We had been married 13 years. But he had the shakes before I met him.

So we went that year, and he was diagnosed as having Huntington's, and it has just progressively gotten worse. And if he could tell you, which he was trying to a minute ago, he was saying, shaky, shaky, shaky, because that is what his body does all the time.

Senator HARKIN. And is there any medicine that can be given?

Mrs. STOWERS. No; there is no medicine.

Dr. FALEK. Paradol is the medication of what one might call choice at the moment. But it is not very much a choice.

In very few patients, it limits or inhibits some of the movement for a portion of the time. But it is only a portion of the time that it limits the movement. So for most patients the movement becomes, it starts around the fingers, around the eyes, and then it becomes totally body invasive, both externally and internally.

So the patients feel the movement in all portions of their body. And usually they stop speaking early because the epiglottis is moving. So they have no control over the speech.

Senator HARKIN. So Mr. Stowers cannot speak?

Mrs. STOWERS. He does speak, but it is very difficult to understand him.

Senator HARKIN. How about sleep? Is there sleep?

Mrs. STOWERS. When he is totally asleep 100 percent, then there is no body movement. But if he has to go to the bathroom or any waking that occurs, his body shakes again. And when he lays down at night he shakes for at least 15 or 20 minutes before he will finally get into sleep.

Dr. FALEK. And no one understands the basis for this.

Mrs. STOWERS. And he wakes all night.

Dr. FALEK. What happens at the end of these patients, eat more and more, they move more and more rapidly, they eat more and more, but at the end they look like cancer patients at the time of death, because apparently there are not enough calories available to keep up with the movement utilization of those calories.

Senator HARKIN. Now, you said that they have pretty much isolated the gene?

Dr. FALEK. They have linked to the gene and they are now less than 1 million base pairs from the gene. But they have not as yet been able to sequence the gene.

Senator HARKIN. So this is one area where long-term care is very necessary.

Dr. FALEK. Yes.

Senator HARKIN. You mentioned the catastrophic illness bill. But that does not really answer the question.

Dr. FALEK. That is right. There is only 150 days in the catastrophic on this bill, and it is a terrible situation for families with members being affected with this disease.

Senator HARKIN. I want to remember this, because I am very interested in long-term care, and I think it is one of the most pressing issues that we have.

Most people think that it only involves the elderly, but there are a lot more individuals who need long-term care.

Dr. FALEK. We have patients with onset at age 4 with Huntington's disease. While we talked about the mean age of onset between 38 and 43, in my population in Georgia the range is from age 4 to age 60 something, say 67 or 68.

Senator HARKIN. Well, how much research did the NIH fund?

Dr. FALEK. In 1986 it was $3.5 million, and in 1988 it is $4.2 million.

Senator **Harkin**. $4.2 million in 1988, total research dollars from NIH for research into Huntington's. Were you asking for an increase in that?

Dr. **Falek**. We would like to at least keep—the concern is how much more support we can get.

There are only two supported centers in the United States now with regard to Huntington's disease. That is the one at Johns Hopkins and the one at Harvard, at Mass General. The first one was the one where the gene was, where the molecular marker was discovered.

Senator **Harkin**. Thank you very much for coming here today and enlightening us as to what Huntington's disease is all about. We will do what we can.

Next we will hear from Terry Lierman on behalf of the National Multiple Sclerosis Society. If Mr. Lierman is not here, is there anyone to testify on behalf of the Multiple Sclerosis Society?

STATEMENT OF ALVIN V. BLOCK, PRESIDENT, ESA, INC.

Senator **Harkin**. Then our next witness will be Alvin Block, president of ESA, Inc. Please proceed.

Mr. **Block**. Thank you, Mr. Chairman and members of the committee. I am Alvin Block, president of ESA, a biomedical research company located in Bedford, MA.

I would like to discuss the SBIR program and its impact on ESA. Over the last 5 years small businesses created all of the net new jobs, and now account for over 50 percent of all the people employed in the United States.

Small business has been a major contributor to new and creative technology innovation, which in turn has helped maintain the U.S. technology lead over foreign competition. ESA has developed a unique instrument, a neurochemical analyzer, which determines hundreds of neurochemicals in a single measurement of a single sample.

These neurochemicals are message carriers between the brain and the rest of the body, reporting to the brain on the state of health of the body, and in return carrying commands from the brain on how the body should react.

We believe this measurement capability represents a significant advance in the state of the art of understanding both the mechanisms of a number of degenerative and effective disorders, and the relationships between the brain and these disorders.

This information may lead to therapeutic intervention, and may also provide a route to possible prevention. These disorders include Alzheimer's, Huntington's, and Parkinson's diseases, and infection, pain, nausea, schizophrenia, depression, and substance abuse.

ESA has been the recipient of five SBIR grants totaling $700,000. The SBIR funding allowed ESA to accelerate the development of this neurochemical analyzer, and its application to medical research.

Major institutions working with the neurochemical analyzer are the Massachusetts General Hospital, McLean Hospital in Belmont, MA, the Bedford, MA, VA Hospital, the San Diego, CA, VA Hospital, and the Eastern Virginia Medical School in Norfolk, VA.

The major focus of the research being done with these analyzers is the investigation of the following. The role of neurochemicals in schizophrenia and depression, the effect of antidepressant drugs on schizophrenia, the mechanism of brain degeneration in both Huntington's and Alzheimer's disease, mechanisms and treatment of degenerative brain processes caused by Alzheimer's and Parkinson's diseases, epilepsy and aging, the effect of blood flow blockage as in stroke on the neurochemistry of the brain, the correlation of neurochemical profiles with early pediatric neuroblastoma, the use of patterns of infectious organisms for early typing and detection of infection, and studies of the neurochemistry of alcoholism.

We are confident that our instrumentation and technology, developed under the SBIR program, will ultimately improve the quality of health care, and with it the quality of life while reducing total health care costs.

PREPARED STATEMENT

We would like to thank the Division of Research Resources, NIH for their continued support of our efforts. I hope that this one story about the successful use of the SBIR program will prompt you to more aggressively support this program in the future. Thank you.

[The statement follows:]

STATEMENT OF ALVIN V. BLOCK

I am Alvin V. Block, President of ESA, a biomedical research and analytical instrument manufacturing company located in Bedford, MA.

Today, I would like to discuss the Small Business Innovation Research (SBIR) Program generally and its impact on ESA specifically. The SBIR Program has been in existence since 1983. Its stated goals are to:

- stimulate technological innovation;
- use small business to meet federal research and development needs;
- increase private sector commercialization of innovations derived from federal research and development; and
- foster and encourage participation by minority and disadvantaged persons in technological innovation.

We believe that the goals of the SBIR Program have been met to a significant extent in the case of ESA.

Over the last five years, small businesses created all net new jobs in the United States. Over this period, they have had a 14% increase in employment and they now account for over 50% of all the people employed in the United States.

It is important to note that small business has been a major contributor to new and creative technology innovation, which in turn has helped maintain the technology lead of the United States over foreign competition.

I would like to tell you about ESA's success with the Small Business Innovation Program. ESA has developed a unique instrument, a neurochemical analyzer which determines a large number of neurochemicals in one single measurement. These neurochemicals are message carriers between the brain and the rest of the body, reporting to the brain on the state of health of the body and, in return, carrying commands from the brain on how the body should react. We believe this measurement capability represents a significant advance in the start-of-the-art of understanding both the mechanisms of a number of degenerative and affective disorders and the relationships between the brain and these disorders. This information may lead to therapeutic intervention in these disorders and may also provide a route to possible prevention. These disorders include Alzheimer's, Huntington's, and Parkinson's diseases, and infection, pain, nausea, schizophrenia, depression and substance abuse.

From 1984 to January 1988, ESA has been the recipient of five SBIR grants totaling $700,000. The SBIR funding allowed ESA to accelerate the development of the Neurochemical Analyzer instrumentation and its application to medical research and further an understanding of a number of brain disorders. These grants shortened the total time to bring this technology to market. There are now seven instruments in the hands of customers and collaborators in addition to five systems at ESA. Major institutions working with the ESA Neurochemical Analyzer are the Massachusetts General Hospital; McLean Hospital in Belmont, MA; the Bedford, MA Veterans Administration Hospital; the San Diego, CA Veterans Administration Hospital; and Eastern Virginia Medical School in Norfolk, VA. The major focus of the research being done with these Neurochemical Analyzers is the investigation of the following:

o biological samples from patients and controls to determine the role of neurochemicals in schizophrenia and depression;

o the affect of antidepressant drugs on schizophrenia;

o brain degeneration in both Huntington's and Alzheimer's disease;

o the mechanism of degeneration in Alzheimer's disease in an attempt toward early diagnosis and treatment;

- o mechanisms and treatment of degenerative brain processes caused by Alzheimer's disease, Parkinsonism, epilepsy and aging;
- o effect of blood flow blockage (as in stroke) on the neurochemistry of the brain;
- o correlation of neurochemical profiles with early pediatric neuroblastoma;
- o use of patterns of infectious organisms for early typing and detection of infection; and
- o studies of the neurochemistry of alcoholism.

ESA is submitting a joint proposal with the Massachusetts General Hospital and the Massachusetts Alzheimer's Center to use the Neurochem Analyzer to create a data base for Alzheimer's and other degenerative disorders. The data base will correlate clinical, epidemiological, and biochemical information to facilitate the early diagnosis of these disorders and develop and evaluate therapeutic intervention.

Initial sales of the instrument began at the end of 1987. ESA has already contributed to improving the balance of the trade deficit in the amount of approximately 30% of our total SBIR grant funding. We have sold two units to Japan which are currently being introduced into the medical research community.

We are confident that our instrumentation and the technology developed under the SBIR Program will ultimately improve the quality of health care and with it the quality of life, and reduce total health care costs which continue to grow at approximately 10% per year.

We would like to thank the Division of Research Resources, NIH, for their continued support of our efforts.

I hope that this one story about the successful use of the Small Business Innovation Research (SBIR) Program will prompt you to more aggressively support this program in the future.

Senator **Harkin**. Thank you very much, Mr. Block. I can assure you as a member of the Small Business Committee that I have been supportive, and your testimony gives me even more reasons to be supportive of the SBIR.

Mr. **Block**. I appreciate the opportunity to testify.

SUBCOMMITTEE RECESS

Senator **Harkin**. Thank you. That ends our witness list for today.

The subcommittee will stand in recess until 9:30 tomorrow morning, when we will continue our public witness hearings.

[Whereupon, at 11:52 a.m., Tuesday, June 7, the subcommittee was recessed, to reconvene at 9:30 a.m., Wednesday, June 8.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1989

WEDNESDAY, JUNE 8, 1988

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:45 a.m., in room SD–192, Dirksen Senate Office Building, Hon. Pete V. Domenici presiding.

Present: Senators Weicker, Hatfield, and Domenici.

NONDEPARTMENTAL WITNESSES

Senator DOMENICI. The subcommittee will please come to order. This morning we will continue the eighth of 9 days of hearings with public witnesses with testimony focusing on programs funded by the Subcommittee on Labor, Health and Human Services, Education and 14 related agencies.

During these several sessions the subcommittee will hear testimony from approximately 225 witnesses, the highest number yet to be heard by the subcommittee in a single year. Because of the large number of witnesses, I regret that we must request that each witness keep their oral testimony brief and you should be assured that your full statement will be included in the printed record.

In order to help us stay on schedule, we are going to use a green-red light system. When the red light goes on, your 3 minutes have expired. We will have to ask each of you to conclude your remarks when that red light goes on so that each witness will have an opportunity to present their views in a fair manner.

STATEMENT OF CAITLIN RYAN, COALITION FOR AIDS PREVENTION AND EDUCATION

ACCOMPANIED BY BILL BAILEY, LEGISLATIVE AFFAIRS OFFICER, AMERICAN PSYCHOLOGICAL ASSOCIATION

Senator DOMENICI. The first witness this morning is Caitlin Ryan with the Coalition for AIDS Prevention and Education.

Would you please proceed. Good morning and welcome.

Ms. RYAN. Good morning. Thank you for this opportunity to testify. In addition to my other positions, I am a community social worker and a chapter board member of the National Association of Social Workers. For my working habits I have been named NSW's national social worker of the year. I have conducted considerable research on the State's response to the AIDS epidemic, and have recently coauthored a review of State expenditures on AIDS. With me is Mr. Bill Bailey, legislative affairs officer for the American Psychological Association.

Today I will present the Coalition for AIDS Prevention and Education, a coalition of 28 national organizations concerned with AIDS prevention. To initiate a comprehensive and effective Federal AIDS prevention and education strategy, we urge your subcommittee to adopt the $1.9 billion budget for AIDS research, prevention, and treatment programs in fiscal year 1989. Our testimony focuses on the critical appropriations needed for ADAMHA.

It has been widely acknowledged that AIDS is a disease of behavior. Although some remarkable successes have been reported in higher incident cities among some gay men, the successes are in no way universal. We must conduct research to identify successful components in existing and potential models and adapt or modify them to use with different populations.

To do this we recommend funding AIDS research within ADAMHA at $90 million. We strongly urge a reordering of ADAMHA AIDS research funding priorities to reduce the current orientation toward neurobiological research with a more concentrated focus on behavior.

In fiscal year 1988, the percentage projected for the PHS budget category of psychosocial factors hovers at a dismal 1.9 percent of the Federal AIDS research budget. We recommend that $67 million of the proposed budget go toward AIDS research at NIMH with an increased allocation toward behavioral, psychosocial, and mental health research. This would improve the program balance which has shifted away from behavioral to a more neuroscience orientation.

We recommend increases for AIDS research at NIDA and NIAAA to expand programs to focus on behavioral issues, including the interaction between substance abuse and high-risk behavior. We recommend funding ADAMHA programs for prevention, education, and treatment at $230 million. This increase would allow ADAMHA to establish a $25 million program to provide mental health services for people affected by AIDS with an increase of $100 million in direct treatment services.

My clinical experience and research indicate the dearth in appropriate services for HIV-infected individuals and their family members nationally. The lack of services is especially critical in low- and middle-incidence areas where AIDS has not been yet identified as a priority. One-time counseling is not enough. Long-term support is essential to help people change this behavior.

We applaud and support the health care provider training programs initiated through ADAMHA agencies. Despite the development of positive training models, my data indicate a continued serious threat of deficit of available high-quality training programs for health and mental health professionals, lack of training and fear among providers, discrimination against patients, and poor-quality care. Still to begin to address this issue by putting State dollars into training programs, however, most of these programs are significantly underfunded and limited in scope.

PREPARED STATEMENT

It is clear from the large support of a variety of organizations that the behavioral agenda for AIDS has been neglected. In order to effectively design a prevention campaign, we must also reexamine our priority setting in this area.

[The statement follows:]

STATEMENT OF CAITLIN RYAN

I am here today on behalf of the Coalition for AIDS Prevention and Education (CAPE), a confederation of national organizations that are concerned with prevention in the context of AIDS. To initiate a comprehensive and effective federal AIDS prevention and education strategy, we urge your Subcommittee to adopt a $1.9 billion budget for AIDS research, prevention and treatment programs in FY 1989. Under our proposal, federal research would be funded at $945 million, prevention activities at $660 million, and treatment programs at $300 million.

Today, I will focus my testimony on the critical appropriations needed for the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA), the Centers for Disease Control (CDC) and the Health Resources and Services Administration (HRSA) - the three arms of the Public Health Service (PHS) most concerned with behavior change, prevention and the mental health aspects of the AIDS epidemic. While other groups will be addressing those portions of the PHS AIDS budget in the areas of research, prevention and treatment not considered here, it is useful to note that the programs I will discuss comprise 57% ($1.1 billion) of our overall AIDS budget request.

Behavioral Science Research Needs

Since the beginning of the AIDS epidemic, it has been widely acknowledged that AIDS is a disease of behavior: IV drug and sexual intercourse are the primary modes of transmission. In the absence of a cure or vaccine, behavior change offers the only means of limiting the spread of AIDS. Moreover, even with the advent of a cure or a vaccine, AIDS will continue to present problems both in terms of those who already are infected and as an infectious, sexually transmitted disease. A recent increase in the incidence of syphillis, for example, indicates that the availability of penicillin, the so-called "magic bullet," has not eliminated the need for behavioral responses to limiting the spread of this disease.

Despite the remarkable achievements we have seen in behavior change among some groups at risk for AIDS - especially gay and bisexual men - we do not yet have the foundation of knowledge necessary to wage a real war against this disease. Federal support of behavioral research, which is chiefly the responsibility of ADAMHA has been seriously curtailed since 1980. As AIDS has proven, the weakened support base for the behavioral sciences has left the nation poorly equipped to deal with the health crisis of AIDS. As if to confirm this trend, the National Academy of Sciences, in Confronting AIDS, stated that:

> ...the forces that shape human behavior, and the best approaches to influencing behavior to protect health, are among the most complex and poorly understood aspects of society's response to the AIDS epidemic...In contrast [with virologic research], the knowledge base in

the behavioral and social sciences needed to design approached to encourage behavioral changes is more rudimentary because of chronic inadequate funding. This lack of behavioral and social science research generates some of the most important and immediate research questions surrounding the epidemic. (Confronting AIDS, pp. 230-31).

At $177 million in the President's FY 1989 budget, funding for the AIDS programs at ADAMHA reflects just 13 percent of the entire funding proposed for AIDS. Moreover, a significant share of these funds is targeted to programs that are service rather than research programs. By lumping together service and research, the focus on necessary scientific investigation in the mental health and substance abuse arenas is further obscured.

CAPE recommends funding AIDS research activities within ADAMHA at $90 million, an increase of 47 percent over the President's budget. We strongly urge that the Subcommittee encourage a reordering of ADAMHA AIDS research funding priorities, replacing the current orientation toward neurobiologic research at each of the ADAMHA institutes with a more concentrated focus on behavior. In FY 1988, the overall percentage spent on the PHS budget category of "psychosocial factors" research at ADAMHA and the National Institutes of Health (NIH) hovered at a dismal 1.9 percent of the federal AIDS research budget. With a reshuffling of priorities, however, the exciting work underway on the action of the virus on the central nervous system and the role of substances of abuse as cofactors in disease progression could continue, but duplication of research efforts with those institutes at NIH examining similar phenomena would be minimized. The expertise of ADAMHA, however, could be used in a consultative fashion with NIH.

National Institute of Mental Health

We recommend an FY 1989 appropriation of $67 million for AIDS activities at NIMH - the federal research Institute with lead responsibility for research on human behavior - and an increased allocation of these resources toward research on the behavioral, psychosocial and mental health aspects of AIDS. Between FY 1987 and FY 1988, the proportion of the NIMH AIDS research portfolio devoted to psychological and behavioral research decreased from 40 percent to 35 percent. Under the President's budget proposals for FY 1989, the projected level of funding for "psychosocial factors" is expected to again remain below 40 percent of the NIMH AIDS budget.

NIMH has indicated that primary attention will be directed at neurovirology including continued attention to AIDS-related dementia and psychoneuroimmunology.. While each of these topical areas is important, each is also the subject of significant research funded by other institutes. The other major areas in which NIMH funds research projects (psychological and behavioral issues, including behavior change, psychological response, coping and stigma), are areas that are central to the Institute's mission. These areas, particularly behavior change, are low priority at NIMH yet are critical to stemming transmission of the epidemic. No other PHS entity has the expertise to address these research issues appropriately.

Under the CAPE recommendations, NIMH would be able to continue its important AIDS work in the neurosciences. More importantly, this funding level would allow for the award of a significant additional number of new and competing research project grants for studies of sexual behavior patterns as well as testing of interventions targeted at specific groups including black and latino gay and bisexual men, persons using drugs and alcohol during sex, adolescents at high risk and ethnic minority women.

This funding increase would also allow for the funding of a research program to develop and test the efficacy of theory-driven interventions designed to modify the behaviors and norms of entire communities. This type of program would borrow from the success of other community-based prevention programs, such as those that have been implemented in San Fransisco and from other areas of prevention research as well. Through such a mechanism, we would be able to determine which elements of successful AIDS prevention programs could be replicated in communities across America.

We are greatly concerned about the federal government's unwillingness to support on sociological and social psychological research. This research is crucial for addressing the unique characteristics of subgroups affected by AIDS (such as gay men and IV drug users) and how social groups respond to the epidemic. Such an research enterprise would look at the effect of social support networks on the development and progression of HIV disease; help to describe the behavior of individuals and subgroups in response to AIDS and the public policies developed as a response to AIDS; and, consider issues of communication, persuasion and attitude development. The Subcommittee should encourage NIMH to develop a significant agenda in this area.

The Other ADAMHA Institutes

CAPE recommends $128 million for AIDS activities at NIDA to assist in expanding the agency's research program in the behavioral sciences. Important work must be done at NIDA in the area of pharmacology and biology, but ultimately IV drug use is an extraordinarily strong, self-reinforcing behavior. Currently, NIDA projects that 50 percent of its overall AIDS research will be devoted to behavioral research in FY 1988 and 1989. But, as the President's Commission on the Human Immunodeficieny Virus indicated, NIDA should also sponsor research on: the characteristics of clients whose success in a particular treatment modality could be predicted, the development of improved and innovative treatment modalitites, and basic demographic questions such as the aggregate incidence of HIV infection and the sexual practices among IV drug users. CAPE's funding proposal for NIDA's activities would go along way toward assisting the agency in meeting these behavioral research needs.

CAPE recommends $8.3 million for AIDS activities at NIAAA in order to expand the share of the Institute's budget (20%) now directed at AIDS behavioral issues. Unfortunately, research at NIAAA has to date focused exclusively on the biological relationship between AIDS and alcohol. It is also important to address the significant relationship between alcohol use and high risk behavior. Moreover, the role of problem drinkers in spreading HIV infection has yet to be seriously considered. NIAAA has only recently issued a request for proposals in this area.

ADAMHA's Role in AIDS Service Delivery

CAPE recommends funding of ADAMHA AIDS service delivery programs for prevention, education and treatment at $230 million, a 98 percent increase over the President's FY 1989 level. This increase would allow for attention to the mental health needs of persons affected by HIV infection and expand the role of the federal government in providing drug treatment services where they are needed.

Increasingly, we have become aware of the long term mental health consequences of HIV disease. The infected asymptomatic individual is faced with the constant prospect of death. The stress of coping with an AIDS diagnosis presents a most difficult challenge for the sick. Special needs of the families and friends of AIDS patients must be considered. This is not only a mental health emergency of the first magnitude, but it also presents serious public health issues. If HIV-infected individuals are to alter their most intimate behaviors we must provide on-going support for maintaining behavior change in order to sustain the remarkable gains we have already achieved. Therefore, our proposal includes $25 million in funding through NIMH for mental health services for persons infected or affected by AIDS.

Linkage of such services to assure that they are provided at the level needed requires improved coordination between mental health providers, primary care providers, and community-based programs. For example, many IV drug abusers do not readily accept referral to mental health services and seldom visit even outpatient health clinics but their families do. Working with community health programs would assure targeting services where they are needed. Community AIDS education programs with a health orientation, health and mental health counseling, and identification and treatment of sexually transmitted diseases are examples of activities which are already in place and ready for expansion through links with community-based clinics, such as the Community and Migrant Health Centers. Present funding for that program, however, barely covers existing services and cannot support new services necessary for significant preventive impact.

Finally, the President's Commission on the Human Immunodeficiency Virus Epidemic made clear the urgent need for expanded treatment for IV drug users. The Commission recommended that drug treatment be available on demand with funding at a level of $1.5 billion. Drug treatment offers one of the best prospects for reducing high risk behaviors and the transmission of HIV among needle substance abusers, their sexual partners, and the perinatal transfer to newborn children. We therefore urge the Subcommittee to provide an additional $100 million over and above funding for treatment through the Alcohol, Drug Abuse and Mental Health Block Grant and the Omnibus Drug Abuse Act supplemental treatment grants.

The CDC: Education, Prevention Services and Testing-related Counseling

CAPE's member organizations applaud the on-going work at the CDC. Our FY 1989 proposed funding level of $705 million, which represents a 76 percent increase over the President's request, will permit an important expansion of many of these on-going initiatives. We urge that CDC work toward a closer collaboration with the research Institutions which conduct behavioral research related to AIDS. For several years now, CDC has funded a demonstration program on the effects of innovative behavioral interventions around AIDS. Details from this research have yet to be released and we urge that the Subcommittee direct CDC to place a priority on the issuance of this invaluable data.

With regard to CDC's prevention efforts, we are concerned that some local service providers are unable to obtain funds from AIDS prevention grants provided by CDC to the states. We urge that the Subcommittee request a report on this issue from CDC. Further, we oppose any consolidation into a block grant of the AIDS prevention and surveillance activities at CDC. Such action would restrict the CDC's ability to target funds where they are most directly needed. Moreover, block grant programs have reduced the Federal government's ability to monitor programmatic expenditures and have virtually eliminated evaluative efforts. It is our understanding that the Administration may attempt to consolidate these programs administratively and we urge the Subcommittee to specify how the prevention and surveillance dollars are to be spent, both for the current fiscal year as well as for FY 1989.

AIDS prevention programs have been inconsistent in reaching various populations. Ignorance about basic transmission and prevention issues persists in the general public. Such education must contain more direct and explicit messages. Data accumulated in the development of CDC's FY 1988 education campaign suggest that the American public is prepared for such explicit education messages when appropriately targeted to the intended subgroups. Furthermore, such messages are most effective in curtailing the spread of AIDS. Any attempts to bind the hands of CDC in responding to the prevention needs of the nation run counter to the best advice of the scientific community.

Adolescents at risk for AIDS often require the most creative forms of outreach and interventions. While school-based effrots are important, many school-aged youth require additonal or more intensive outreach efforts. Ways need to be developed to address the special needs of out-of-school youth and to use the family unit for education. Insufficient effort is devoted to coordinating and evaluating the various education and prevention efforts that occur within a state. Special consideration should be given to the development of mechanisms to ensure coordination and promote high-quality scientific evaluation.

One of the most pressing areas for CAPE member groups is in the area of counseling and testing for the AIDS antibody. In 1987, CAPE issued a statement endorsed by 24 national health and mental health organizations regarding counseling needs in the face of the HIV epidemic. Simply put, it is our contention that the HIV antibody test may be an appropriate adjunct to counseling in the effort to promote behavior change away from high risk practices that transmit infection but that testing must never be conducted

One of the guiding issues behind development of this paper was concern over the possible adverse consequences on individuals associated with HIV testing. Empirical research demonstrates that adverse social and psychological consequences are associated with knowledge of one's positive antibody status, including extreme depression, breakups of relationships, social isolation and in some case disabling levels of anxiety. The development of major depression among those who have tested positive to HIV is particularly troubling given the high rates of suicide among the HIV infected.

While the human costs associated with conducting the test in the absence of counseling are great, there are also serious flaws in such an approach from a public health standpoint. We have reports of military recruits, who after receiving testing without counseling continue to engage in high risk activities. Despite the exhortation of the public health community for some time now, research is documenting that providers often administer the test without providing appropriate counseling.

Thus, we strongly urge an appropriation of at least $200 million, a doubling of the President's request, in order to allow CDC to expand its existing counseling and testing program to locations beyond the existing anonymous testing sites and sexually transmitted disease clinics. Testing would appropriately be conducted on a voluntary basis in family planning, prenatal care and drug abuse clinics.

HRSA: Mental Health, Protection and Advocacy Services

CAPE recommends funding for HRSA at $155 million in FY 1989. Through the provision of direct health services to persons who may not otherwise receive care, HRSA has played a major role in helping to ameliorate the plight of persons with AIDS. In particular, the award of the thirteen AIDS Service Demonstration Project grants to metropolitan areas with the highest cumulative prevalence of AIDS has helped to allow those cities to more effectively develop comprehensive systems of care. CAPE urges continued development of this program and we urge more explicit inclusion of mental health services in all of the grants made through the demonstration program and the specific evaluation of the effectiveness of the mental health components of these programs in meeting patient needs.

Consistent with the work undertaken through the demonstration grants, the level of funding provided to HRSA under the CAPE recommendation would allow establishment of a program of legal advocacy services to persons with HIV infection. People with HIV infection face discrimination in a variety of situations, including employment, housing, health care and insurance. This discrimination not only causes severe consequences for the affected individuals but also creates a serious barrier to public health efforts to prevent the transmission of the disease. The real or perceived fear of discrimination has prohibited many persons from seeking education, testing and counseling and health services thereby defeating opportunities for prevention intervention.

Senator DOMENICI. Thank you very much. Your statement will be made a part of the record. Senator Inouye asked if I would inquire with reference to two issues.

Do you see a relationship between the increased need for provider education and training in AIDS and an increased need for funding NIMH's clinical training program?

Ms. RYAN. There has not, today, been a national comprehensive professional education campaign. Health care workers have been inconsistently trained and many are frightened and uncertain in terms of how to work with AIDS patients. We are in desperate need of training to reduce this fear. Even though the NIMH has developed some new training models, those have not been made available to all of the providers in the United States that really need them. All providers at all levels need to be trained and this generally does not occur.

Senator DOMENICI. Could you just give us another 30 seconds of an explanation in a little more detail on why you think it is important that NIMH reorder its priorities for AIDS research?

Ms. RYAN. NIMH is a Federal agency with lead responsibility for research on human behavior. However, AIDS is their fourth priority after schizophrenia, decade of the brain, and effective disorders even though AIDS is the single largest item in the research program. The Institute believes that AIDS is a disease of the brain and research priorities reflect that. Neurovirologists see complications in the area of immunology. We certainly don't disagree that these are very important areas, but other institutions in the Federal infrastructure have lead responsibility for this research agenda. If we decide, as we have certainly recommended, that behavioral change is our most critical need of addressing this epidemic, then someone within the Federal Government needs to take primary responsibility to approve those tools in this research area.

Senator DOMENICI. Is Irvin Muszynski, National Association of Addiction Treatment Providers, here? He has not submitted testimony. If he does within a reasonable time we will make it a part of the record.

STATEMENT OF CHRISTINE LUBINSKI, WASHINGTON REPRESENTATIVE, NATIONAL ASSOCIATION ON ALCOHOLISM, INC.

Senator DOMENICI. Next is Christine Lubinski, Washington representative, National Council on Alcoholism, Inc.

Good morning. I am sorry we have to keep you on such a tough schedule.

Ms. LUBINSKI. That's OK. I will give it a try. I feel like I am running the marathon.

My name is Christine Lubinski. I am the Washington representative for NCA, which is the oldest and largest health agency, volunteer health agency working nationwide to reduce alcoholism, alcohol-related problems, and other drug-related problems. Because of the brevity of my testimony I would like to confine my remarks to talking about the alcohol, drug abuse, and mental health services' block grant and the National Institute on Alcohol Abuse and Alcoholism.

Let me say that NCA does lend its support to the appropriations' recommendations of over 20 organizations in the alcohol, drug abuse, and mental health fields. We also strongly support the expansion of the Office of Substance Abuse Prevention's Grant Program to include populations other than high-risk youth.

In an environment permeated with alcohol and other drugs, everybody is at risk, including youth who do not fit behind this profile, as well as women, minorities, and other adult populations. Since all alcohol and drug prevention activities are consolidated at OSAP, it is important that OSAP's focus be broadened if the prevention needs of all populations are to be met.

Historically NIAAA's research budget has paled in comparison to Federal research efforts for other illnesses despite alcohol's very substantial contribution to mortality and morbidity. Recent increases in NIAAA's budget must be continued if the recent and declared war on drugs is to begin to effectively address the Nation's leading drug problem: Alcohol.

NCA encourages the subcommittee to appropriate $102.1 million for NIAAA's research budget. We support a comprehensive approach to research and believe that the additional money will allow this to happen.

In the area of new institute initiatives we urge the subcommittee to appropriate $15 million for the continuation of the NIAAA/NIDA Homeless Demonstration Program. The purpose of these demonstrations is to develop, document, and evaluate all available alcohol and drug treatment services delivery programs for the homeless without the many drug problems. Two of these projects are targeted specifically for the homeless, mentally ill, alcoholic, and drug addict. Continued support for these programs will bring needed services to this desperately underserved population.

We also recommend an appropriation of $2 million to establish an NIAAA research study on women. Few research studies on alcohol and alcohol-related problems have included women. Even when women have been included, the number has often been too small for statistically valid generalizations and comparison.

Federal funding and leadership are needed to support research efforts on women. A line item for an important new research center on women, alcohol, and other drugs of $2 million will greatly enhance scientific and public knowledge about women suffering from, or at risk for, alcohol and other drug problems.

We join other organizations in the alcohol, drug abuse, and mental health fields in a request for an appropriations level of $601.5 million for the ADMS block grant, and $190 million for the supplemental alcoholism and drug abuse treatment grants.

PREPARED STATEMENT

The national focus on the Nation's drug crisis has demonstrated the inadequacy of the Nation's public treatment system and needs continued Federal funding, if we are serious about winning the war on drugs.

Thank you very much.

[The statement follows:]

STATEMENT OF CHRISTINE LUBINSKI

The National Council on Alcoholism is the leading voluntary health organization working nationwide to prevent and reduce alcoholism and other alcohol and drug related problems. Founded in 1944, NCA's major programs include prevention and education, public information, medical/scientific information, public policy advocacy, conferences, and publications. NCA's 200 state and local nonprofit affiliates conduct similar activities.

The federal programs under consideration in these hearings represent the heart of the federal effort to reduce and prevent alcoholism and other drug problems in American society. NIAAA and NIDA represent the research backbone of the federal commitment to reduce the toll of alcohol and other drug problems. The Alcohol, Drug Abuse and Mental Health Services block grant serves as the primary source of prevention and treatment funding to states, funds which are translated into public alcoholism and other drug prevention and treatment services in communities across the nation. The Office for Substance Abuse Prevention and the Emergency Supplemental Treatment Grants, both authorized under the Anti-Drug Abuse Act of 1986 and the NIAAA Homeless Demonstration Projects authorized under the Stewart B. McKinney Homeless Assistance Act represent the most recent developments in a comprehensive federal plan to address these major health and social problems.

NCA would like to focus its testimony on issues pertinent to appropriations for NIAAA and the ADMS block grant. Particular areas of concern for NCA are the women's set-aside of the ADMS block grant and the NIAAA homeless demonstration projects. Before focusing our testimony on these issues, NCA lends its support to the appropriations recommendations of over twenty organizations in the alcohol, drug abuse and mental health fields for NIDA and the Office of Substance Abuse Prevention. Those recommendations include an appropriation level of $296.5 million for NIDA research, $128 of which will be devoted to AIDS research, and a fiscal year 1989 funding level for OSAP of $62.5 million, which includes $41.4 million for OSAP Substance Abuse Demonstration Projects. The grants for high risk youth should be maintained at $27.2 million with an additional $14.2 million provided for demonstration grants for other populations including youth who do not fit the high-risk profile, as well as women and minorities. Since all of the federal alcohol and drug prevention activities have been consolidated at the OSAP level, it is important that OSAP's focus be broadened if the prevention needs of all populations are to be addressed.

National Institute on Alcohol Abuse and Alcoholism

Historically, the NIAAA research budget has paled in comparison to federal research efforts for other illnesses, despite alcohol's very substantial contribution to mortality and morbidity and an annual economic toll on the nation of well over $116 billion. Recent increases in the NIAAA budget must be continued if the recently declared "war on drugs" is to begin to effectively address the nation's leading drug problem -- alcohol.

The National Council on Alcoholism encourages the Subcommittee Members to appropriate $102.1 million for the NIAAA's research budget. This would allow for new and competing research grants, including funding for the evaluation of various prevention and treatment approaches. NCA supports a comprehensive approach to research. NIAAA research must go beyond biomedical concerns and evaluate various approaches to the prevention and treatment of alcoholism and alcohol related problems. NCA supports an appropriation of $8.3 million for AIDS research to be conducted at NIAAA. In addition NCA supports an appropriation of $3.9 million for research training, at least $1 million for clinical training and $11.9 million for direct operations.

In the area of new Institute initiatives, NCA urges the Subcommitee to appropriate $15 million for the continuation of the NIAAA/NIDA Homeless Demonstration Programs. This appropriation will support 10 existing projects and 20 new demonstration projects for a one year period. The purpose of these demonstration projects is to develop, document and evaluate innovative alcohol and drug treatment and services delivery programs for the homeless with alcohol and other drug problems. Two of these projects are targeted specifically for the homeless mentally ill alcoholic and drug addict. Continued and expanded support for these demonstration projects will bring needed services to this desperately underserved population.

NCA recommends the appropriation of $2 million to establish a NIAAA research center on women. Few research studies on alcoholism and other alcohol related problems have included women and even when women have been included, the number has often been too small for statistically valid generalizations and comparisons. Research on alcohol's effect on the body and national surveys of alcohol consumption usually fail to take into account sex differences in body weight and body water content. Because there is a paucity of data, the assumption is too often made that women have the same problems with alcohol as do men.

Federal funding and leadership are needed to support research efforts on women. A line item for this important new research center of $2 million will greatly enhance scientific and public knowledge about women suffering from or at risk for alcohol and other drug problems.

Alcohol, Drug Abuse and Mental Health Services Block Grant

The National Council on Alcoholism joins other leading organizations in the alcohol, drug abuse and mental health fields in a request for an appropriations level of $601.5 million for the ADMS block grant and $190 million for the Supplemental Alcoholism and Drug Abuse Treatment Grants. The national focus on the nation's drug crisis has brought into sharp relief the inadequacy of the nation's public treatment system to serve all of those individuals seeking treatment for alcoholism and other drug dependencies. The AIDS crisis has exacerbated this situation. We strongly support full appropriations for the $75 million Senate authorization for AIDS included in the ADMS block grant and urge that this money be allotted to cities in the country with the highest proportion of individuals who are IV drug users. Emergency funds were appropriated in the 1986 omnibus anti-drug initiative to aid in reducing waiting lists for alcoholism and drug abuse treatment in many areas of the nation. This money has served to augment a grossly underfunded federal treatment program and must be continued.

The women's set-aside of the ADMS block grant was authorized in 1984 as a vehicle to expand public prevention and treatment services available to women with alcoholism and other drug dependencies. Continuation of the set-aside is critical for the future of these programs. Continuation grants will be particularly important for women's treatment services, allowing them additional time to establish themselves in communities and to identify additional funding sources.

The National Council on Alcoholism is pleased to pledge its continued support for federal alcohol and other drug research, prevention and treatment initiatives. A strong federal commitment beginning in the early 1970's has made great gains in alcoholism and other drug research, prevention and treatment possible. A continuation and enhancement of that commitment are essential to progress.

STATEMENT OF JAMES HOWE, THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

Senator DOMENICI. Before you start, Mr. Howe, looking down our list here, do we have any other witnesses who are going to speak to the same subject that James Howe is going to speak?

Mr. HOWE. We have a witness from the Mental Health Association, one from the American Psychological Association, and one from the American Psychiatric Association and one from the American College of Neuropsychiatry.

Senator DOMENICI. Are they all on our list here?

Mr. HOWE. I believe they are.

Senator DOMENICI. Let's delay Roger Meyer from the Connecticut School of Medicine. Senator Weicker may very well make it here shortly in which event we would like await his arrival for Roger Meyer's testimony. We will also delay Eleanor Kohn's testimony for Senator Weicker in the event he arrives here shortly. So after Mr. Howe, we may proceed with Dr. Lipsitt from Brown and Dr. Sabshin, American Psychiatric Association.

All right, let's proceed with you first, Mr. Howe.

Before the witnesses testify, let me make a couple of observations with reference to the entire morning's testimony and all of the causes that are being advocated so that you will understand a little better, perhaps, the very difficult predicament that Chairman Chiles and ranking member Weicker have in this subcommittee.

I am not sure that this year's process is yet understood. What happened this year is that when we agreed on the economic summit conference and it is now binding and being implemented in both Houses. This is very different from anything we have done in the past.

First of all, as a general principle we decided that the budget of the United States would go up on average more or less about 2 percent. From that figure we arrived at a number for defense, which was about $33 billion less than the administration was going to request. Then we agreed on a foreign assistance number for all of America's foreign aid, and that was less than the administration had been requesting.

Then we agreed on a number, both budget authority and outlays, for all of the remaining discretionary appropriated accounts of this country. The budget process went through a tentative allocation amongst the various functions of Government of that $148.2 billion available for domestic discretionary programs.

We distributed that among the functions of Government and then Congress voted for that guideline. You all should understand that this guideline was not binding. The Appropriations Committees, in the respective Houses, were bound by the budget's defense number; in other words, we couldn't take anything out of it for domestic this year. We were bound by the budget's foreign aid number. But the Appropriations Committee is not bound by the allocation of the $148.4 billion available for all domestic discretionary programs.

The appropriators then decided among their domestic subcommittees how they would allocate that money. I regret to tell you that the bulk allocation that is being made available to this subcommittee was less than the amount the Budget Committee's had in mind. In other words, the appropriators put more in other functions of Government, energy and water and research that goes on there, transportation, et cetera.

So Senator Chiles starts with a total number that is less than we had allocated in the budget process. We know that within Labor and Health and Human Services, the causes you are talking about are now competing for money with all of those domestic programs within this subcommittee's jurisdiction.

You have some tall competitors. You have the national educational programs that we have to fund and for which an increase is being sought. To the extent that there is an increase there, it has to come only out of the remaining accounts that we are here talking about. In that framework, I have to tell you this is going to be a very difficult year.

I might just share a last observation. It is very interesting to me that on the floor of the U.S. Senate we are considering the catastrophic health insurance coverage bill. We did decide to raise taxes and premiums to pay for it.

However, we didn't take any of that new money for that entitlement to use on research or preventive medicine. We are going to just pay the bills for the chronically ill who have hospital and drug bills that exceed what we used to pay for.

It seems to me from what I have heard and what I am going to hear here today that much of what we are going to be paying for in that catastrophic area comes from illnesses for which research funds are being sought here. Breakthroughs could be made and, perhaps, save substantial amounts of money on the chronic illness coverage, but we have not yet devised a mechanism for trading these off.

It seems to me the cost/benefit ratios could be enormous if we could take some of the new funding in the kind of research that we are going to be hearing about. I am certain we would end up saving over the long run as compared with minimal research programs which it seems to me we are going to be saddled with for a while based upon what I have just told you.

Having said that, we welcome the three of you and we are sorry that we are going to have to hold you to the rules, but let's proceed with James Howe from the National Alliance for the Mentally Ill. We are delighted to have you here.

Mr. **Howe**. Thank you very much, Mr. Chairman. On behalf of NAMI, the National Alliance for the Mentally Ill, which is a national network of families whose lives have been directly affected by a mentally ill relative, I would like to thank you for the opportunity to share some of our views with you this morning, especially on the national plan for schizophrenia research and the neurosciences initiative which were released by the NIMH, by the National Advisory Committee of the NIMH in early February.

We certainly do recognize the tight fiscal constraints that this subcommittee has placed on it. Certainly not all things are possible, but that is not to say that nothing is possible. We think that the neurosciences plan, the national plan for schizophrenia, the research budget for NIMH is possible even within the framework of your constraints.

These plans represent the best thinking of the collective genius of scores of America's best scientists and administrators brought together by the NIMH.

All they need now to become reality is the political will of those who hold the purse strings in the Congress. We emboss those plans along with our colleagues in the Mental Health Liaison Group and the Citizens Consortium for Developmental Disability.

NAMI specifically requests this subcommittee to approve funding for non-AIDS-related research for the NIMH in the amount of $400 million in the fiscal year 1989 and we believe that we should be thinking forward to the next year when we think an increase to the $500 million level is warranted.

The subcommittee has already endorsed the concept of accelerated research on schizophrenia. Last year your committee report stated:

> The development of a national plan for schizophrenia research is an important step in building on the research breakthroughs recently made. The committee urges NIMH to implement the national plan upon its completion.

Of course the next logical step is to commit the resources to do the job. When we look at our record in funding research on mental illnesses, it is clear that we are being penny wise and pound foolish. The cost to State governments of caring for severely mentally ill citizens comes to about $7 billion a year. Despite these great sums, the State budgets need to be doubled and doubled again and even then many of our mentally ill citizens will still be suffering.

Why? Because medical treatment of mental illnesses is so far from satisfactory and, of course, the answer to this problem is very clear: We need much more research to get better treatments.

The problem of mental illness costs this Nation's economy more than $70 billion a year and we are spending less than one-half of 1 percent of that amount on research to resolve the problem. No successful corporate CEO would dare present a research budget with such starvation figures to the corporation's board of directors.

PREPARED STATEMENT

An increase to $400 million and then to $500 million would be a prudent investment purely from a national economic point of view, and from a humanitarian point of view its logic is equally powerful because, after all, the brain is the one organ in our body that most clearly sets humans apart from, and gives them dominion over, all of the other creatures of this Earth. It is too important an organ to be neglected.

Thank you.

Senator DOMENICI. Thank you very much.

[The statement follows:]

STATEMENT OF JAMES HOWE

On behalf of the National Alliance for the Mentally Ill, a national network of families whose lives have been directly affected by a mentally ill relative, I would like to thank you for the opportunity to share some of our views with you this morning.

I am particularly pleased to be here today because we stand on the threshhold of an historic occasion--the launching of two bold new initiatives that can break through the stigma and centuries of ignorance that have kept persons with mental illness on the margins of society. I am speaking, of course, about the National Plan for Schizophrenia Research and the Neurosciences Initiative which were released by the National Advisory Committee on Mental Health in early February.

These intiatives are destined to be the twin flagships in the Armada of the National Institute of Mental Health, opening opportunities for scientific advances which will benefit all persons suffering from brain diseases, restoring hope that we may someday soon find efficacious ways of actually preventing mental illnesses--a goal that has eluded us because we have lacked an understanding of some of the basic issues surrounding the functioning of the human brain.

We recognize the tight fiscal constraints placed upon this Subcommittee and the Congress as a whole. Not all things are possible. But to say that is not to suggest that nothing is possible. And as you confront the difficult choices before you, I would urge you to remember that the Neurosciences Plan and the National Plan for Schizophrenia are possible, even within the framework of your constraints. They represent the best thinking of the collective genius of scientists and administrators at the National Institute of

Mental Health. And all they now need to become reality is the political will of those who hold the purse strings in the Congress. We endorse those plans along with our colleagues in the Mental Health Liaison Group and the Citizens Consortium for Developmental Disabilities. And we stand ready to assist you in your efforts to implement them over the next decade.

NAMI specifically requests this Subcommittee to approve funding for non-AIDS related research for the National Institute of Mental Health in the amount of $400 million in Fiscal Year 1989, with a further increase in FY 1990 to the $500 million level. This is approximately $130 million more than the President's request, which seems startling at first glance. But it is important to keep in mind that the President's request is $25 million below what is necessary just to keep current research activities funded. And the President's budget was prepared before the two initiatives were completed and could not reflect their budgetary impact.

This Subcommittee has already endorsed the concept of accelerated research on schizophrenia. Last year, your Committee Report stated, "The development of the national plan for schizophrenia research is an important step in building on the research breakthroughs recently made. The Committee urges NIMH to implement the national plan upon its completion. . . ." The next logical step is to commit the resources to do the job.

When we look at our record in funding research on mental illnesses, it is clear that we have some catching up to do. We are currently spending over $1000 per affected individual for research on muscular dystrophy; $300 per person on cancer; $161 per person on multiple sclerosis; and only $10 each per person for schizophrenia research and research on the major depressive disorders. With 2.5 million Americans suffering from schizophrenia and over 14 million diagnosed as having an affective disorder, we desperately need solutions proportionate to the problem. The two new NIMH research initiatives move us in that direction.

While research is clearly NAMI's number one priority, there are other budgetary items of importance to us. Most of these are captured in the Mental Health Liaison Group document which should be in your possession. It represents the consensus of all of the major advocacy and professional groups involved in the field of mental illness, and we commend it to your attention.

We would particularly draw your attention to a small item which was overlooked by the House during last year's appropriations mark-up, and saved only through the last minute intervention of this Committee. I am referring to the planning grants to states to assist them in carrying out the requirements of PL 99-660. Under LP 99-660, states are mandated to develop plans to establish and implement organized community-based systems of care for seriously mentally ill individuals. This landmark legislation has focused needed attention on services delivery systems, helping to move us away from the fragmentation of care which has characterized mental health treatment in the past.

This legislation was passed with the expectation that Congress would appropriate funds to enable states to implement the planning requirement. The law authorized $10 million to be appropriated for this purpose, establishing a minimum allotment of not less than $150,000 per state. But last year, the House overlooked this implied promise to the states. Fortunately, the Senate did include $5 million in its appropriation and this was the figure accepted in

Conference, after a slight adjustment to $4.8 million to accommodate the Budget Summit agreement. The final FY 1988 figure, however, was not enough to meet the minimum allotment, and barely enough to permit the states to do a creditable job of start-up planning under the Act. This year, we again ask the Subcommittee to fund the state grants at their full authorized level of $10 million, to assure the continuation of this important activity. And we would like to express our deep appreciation for your past defense of the planning act.

Since so many persons with mental illnesses continue to be without adequate services, we believe it is vital for the Congress to continue its commitment to the homeless initiatives undertaken last year and to the Community Support Programs which have been one of the great success stories in the effort to focus community attention on the seriously mentally ill. On both of these fronts, there is increasing evidence of the efficacy of self help programs and we hope the Committee report will reflect a recognition of their value. But we also think it is important to build into all services and demonstration programs a rigorous services research component that will tell us what is working and why. Far too many "demonstration" projects lack any scientific assessment of their outcomes. Head counts are too often substituted for substantive evaluation. Projects come and go without anyone learning very much from their "demonstration." NAMI believes in accountability for the expenditure of public dollars and urges you to help assure that accountability through support for sound services research.

We could, Mr. Chairman, continue through the litany of vital activities of the National Institute of Mental Health, but I am sure you know that NAMI values the full range of the

Institute's mission and supports adequate funding for it to continue its work. We would be remiss, however, if we did not point out our concern that the infusion of AIDS dollars into the Institute not detract from NIMH's primary responsibility to those millions of our citizens who are not AIDS victims, but are instead the victims of a more ancient, and currently more widespread horror--serious mental illnesses. AIDS, even when it is accompanied by dementia, is not primarily a mental illness, and we do a disservice to both populations in need when we confuse their distinct needs within a single services delivery system or research entity. We support the national effort to find a cure for AIDS and we endorse the campaign to eradicate this terrible disease. But we ask that our mentally ill but non-HIV-infected sons and daughters, too, be accorded a comparable priority on the nation's health agenda.

And, Mr. Chairman, we recognize that persons with serious mental illnesses may, themselves, constitute a high-risk group for HIV-infection. Mentally ill persons frequently reside in congregate living arrangements and shelters, where they may be vulnerable to sexual attack. They frequently self-medicate through substance abuse. They can be highly suggestible and their illnesses sometimes lead them down irresponsible paths. But no one is currently looking at this population, collecting incidence and prevalence data, designing education and AIDS prevention programs. Our hope is that this Subcommittee, as it reviews the AIDS budget for NIMH, will recognize that the mentally ill are a neglected at risk population and support at least some attention to the impact of AIDS upon persons with mental illnesses. There is increasing anecdotal evidence that AIDS among the mentally ill is more than a theoretical problem.

But we need, at a minimum, to obtain statistical information that does not exist at the present time. You can help fill that research gap and we would encourage you to do so.

Finally, let me conclude as I began--with a plea for expanded funding for research in basic brain sciences and schizophrenia. It is not enough to provide equal percentage increases between NIMH and the National Institutes of Health. Parity cannot be achieved in this fashion when the research budgets start from unequal bases. Equal percentage increases will only perpetuate inequities. If mental illness is to attain its rightful place on the nation's research agenda, this is the time to eliminate the funding bias against it.

It is also, in our judgment, time to return the National Institute of Mental Health to the National Institutes of Health. We are continuing to press our campaign to accomplish this objective in order to further strengthen research on mental illness. We believe NIH is the most hospitable environment for rigorous scientific inquiry. It is the premier research agency in the world and an appropriate home for the schizophrenia and brain research which will be stimulated by the NIMH initiatives for which we seek your support.

For millenia, persons with mental illnesses have been locked inside the horror chambers of their minds. We have had no cure. We have not known the causes. Our dilemma has been to treat the symptoms, knowing we could not release those held captive of brain diseases. Now we have identified genetic markers for certain mental illnesses. We have new imaging techniques. Science is again interested and primed for aggressive investigation in the area. The door is open a crack and we can see the light of hope just beyond our reach.

The only way out of our dilemma is through that door. This year, we can take the first steps in that direction by funding the NIMH research agenda.

You have started us along that path, Mr. Chairman. And with the continued help of this Subcommittee, I am confident we will cross that threshhold.

Thank you.

STATEMENT OF LEWIS P. LIPSITT, PH.D., BROWN UNIVERSITY, AMERICAN PSYCHOLOGICAL ASSOCIATION

Senator DOMENICI. Dr. LIPSITT.

Mr. LIPSITT. Mr. Chairman and members of the subcommittee, I am Dr. Lewis P. Lipsitt, professor of psychology and medical science, and director of the Child Study Center at Brown University. I am also a former visiting scientist at the National Institute of Mental Health and a former chairman of the board of scientific affairs of the American Psychological Association, a professional and scientific organization representing 90,000 psychologists in the United States.

I also want to point out that the funding levels recommended by APA are supported by a coalition of over 40 organizations involved in alcohol and drug abuse and mental health research, education, training, and service delivery.

Mr. Chairman, I am here today to ask that your subcommittee recommend a fiscal year 1989 appropriation of $400 million for the NIMH Research Program in addition to the important funding for NIMH AIDS research which is proposed in another part of the Department of Health and Human Services budget. This amount represents the best scientific and professional judgment of the needs of behavioral, biological, and social research at this juncture of knowledge and opportunity in the mental health field.

The new Director of NIMH, Dr. Lewis Judd, has stated that we are about to enter a golden age in the mental health field. Rapid advances in our present knowledge of depression, schizophrenia, and other major mental disorders are not only likely, but also an inevitable result of an accelerated Federal investment in the NIMH Research Program.

The generous investment made in recent years by Congress in NIMH research has been a wise one. Our knowledge base and understanding of mental and addictive disorders has been vastly expanded. We are on the verge of further breakthroughs in unraveling the complex mechanisms underlying depression, anxiety disorders, schizophrenia, and other major mental disorders, interpreting the interface between brain function and human behavior and enhancing our understanding of linkages between behavioral risk factors and specific mental and physical disorders.

As a psychologist who has received extramural support from NIMH and who has worked in the NIMH intramural program as well, I would like to call attention to the need for additional research in the area of prevention which you, yourself, have addressed this morning.

My own area of research focuses on what I call human behavioral misadventures. Major threats exist to the lives and safety of large numbers of individuals which are due to such behavioral misadventures.

Accidents, suicide, and homicide, for example, are the major killers of teenagers and young adults. Drinking, drug, and eating disorders account for large numbers of additional deaths and disabilities.

The fact is, however, that most persons who become debilitated or die prematurely are not victims of disease as such, but of behavioral and environmental conditions which are, in principle, controllable.

A large research frontier awaits the alcohol, drug abuse, and mental health field in the areas of self-regulation, understanding risk-taking behavior, and impulse control. The funding levels recommended by the American Psychological Association for our NIMH research activities would permit more scientific attention to these issues.

Vigorous support must also be provided by Congress to the National Institute on Drug Abuse, and the National Institute on Alcohol Abuse and Alcoholism.

APA recommends $150 million and $120.1 million, respectively, in research funding for these agencies in fiscal 1989.

PREPARED STATEMENT

Any war on drugs and alcohol abuse can only be effectively waged with a better understanding of the complex biological, psychological, and social factors that reinforce drug-craving and drug-using behavior and with more effective treatment methods to reduce drug and alcohol dependency.

Greater Federal support for research on these issues is much needed.

Thank you very much.

Senator Domenici. Thank you, Doctor. Your entire testimony will be made a part of the record.

[The statement follows:]

STATEMENT OF LEWIS P. LIPSITT

Mr. Chairman and members of the Subcommittee, I am Dr. Lewis P. Lipsitt, Professor of Psychology and Medical Science, Department of Psychology, and Director of the Child Study Center, at Brown University. I am also a former visiting scientist at the National Institute of Mental Health (NIMH) and a former chair of the Board of Scientific Affairs of the American Psychological Association (APA), a professional and scientific organization representing 90,000 psychologists in the United States. I am pleased to testify today on their behalf on the subject of fiscal year 1989 funding for the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA).

The funding levels advocated by APA were developed by the Mental Health Liaison Group - a coalition of over 40 organizations involved in alcohol, drug abuse and mental health services delivery, research, education and training. These groups represent many diverse entities including psychology, psychiatry, nursing, community mental health centers, consumer advocates and others. We share, however, a common purpose in working together to support the programs administered by ADAMHA. Estimates by the Institute of Medicine indicate that 30 to 45 million Americans suffer from mental or addictive disorders and that the associated health and economic costs exceed $185 billion annually. A quantum leap forward in the federal investment in research to conquer these disorders is needed to arrest this terrible drain on human and economic resources.

NIMH RESEARCH

APA recommends $400 million for NIMH Research (excluding AIDS research) in FY 1989. This amount represents the best scientific and professional judgement of the needs of behavioral, biological, and social research at this juncture of knowledge and opportunity in the mental health field. In fact, the new director of the NIMH, Dr. Lewis Judd, has stated that we are about to enter "a golden age" in the mental health field. Rapid advances in our present knowledge of depression, schizophrenia, and other major mental health disorders are not only a likely, but also an inevitable result of an accelerated federal investment in the NIMH research program.

A significant increase in real spending, rather than a marginal increment, is needed to permit NIMH to implement exciting and long-awaited new initiatives in FY 1989 targeted toward schizophrenia and the neurosciences. The historic and comprehensive "National Plan for Research for Schizophrenia" will focus on the possible behavioral and biological causes of schizophrenia, and on ways in which this disorder can be prevented. The contributions that psychologists are making in schizophrenia research parallel our increasing awareness that a complex combination of psychological, social and genetic factors contribute to the development of this disorder.

The "Decade of the Brain" initiative, spearheaded by Congressman Conte, represents unique opportunities to build upon our rapidly developing knowlege of brain development, learning and memory processes, emotion, cognition, and more. Here, too, psychologists will be intimately involved in research at the interface of brain function and human behavior and at the verge of breakthroughs related to the organization of the brain, the central nervous system, and cognitive functions.

Other priorities for additional study and support by NIMH concern research on mental disorders of childhood and adolescence; mental disorders of the elderly, including the psychosocial aspects of dementia; research on antisocial and violent behavior, including antigay violence; research on linkages between behavioral risk factors and specific mental and physical disorders and diseases; research on anxiety disorders; and prevention research.

As a psychologist who has received extramural support from the NIMH, and who has worked in the NIMH intramural program as well, I am particularly interested in the area of prevention. My own area of research focuses on what I call "human behavioral misadventures". Major threats exist to the lives and safety of large numbers of individuals which are due to such behavioral misadventures. Accidents, suicide and homicide, for example. are the major killers of teenagers and young adults. Drinking, drug and eating disorders account for large numbers of additional deaths and disabilities.

The fact is however, that most persons who become debilitated or die prematurely are not victims of disease as such, but of behavioral and environmental conditions which are in principle controllable. A large research frontier awaits the alcohol, drug abuse and mental health fields in the areas of self regulation, understanding risk taking behavior, and impulse control.

Still another increasingly important research activity carried out by the NIMH involves mental health service systems research and data collection activities. These activities include the only national source of data on the mental health service delivery system. They also include research focused on delivery systems and financing mechanisms which support the provision of mental health services. Last year, APA supported the Subcommittee's action to earmark in report language additional funds for research on issues related to the financing and delivery of services. We urge you to again accord special attention to important area of research.

NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM (NIAAA) AND NATIONAL INSTITUTE ON DRUG ABUSE (NIDA) RESEARCH

APA recommends $150 million for research at NIDA and $120.1 million for research at NIAAA in FY 1989 (excluding AIDS research). In a landmark study by the Institute of Medicine (IOM), it was concluded that the elimination of drug abuse and related problems will best be accomplished through greater knowledge of complex biological, psychological, and social factors that reinforce drug-craving and drug-using behavior. Yet, the Administration's request to reduce the research budget at NIDA by $4 million to $104 million in FY 1989 does not provide adequate funding desparately needed to address this serious and pervasive problem in American society.

The insufficient federal investment in research at NIAAA is also of concern to behavioral scientists. While the Administration has requested to increase the NIAAA research budget to $83.1 million, this amount is still considerably below the funding needed simply to maintain the current level of effort in such vital areas as developing animal models of alcohol-related behaviors, and determining the efficacy of treatment methods for patients at different levels of alcohol abuse and dependency.

ADAMHA RESEARCH TRAINING

APA recommends that Congress appropriate $26.2 million in FY 1989 to support a total of 1,100 research trainees at NIMH and increase support for predoctoral behavioral research training awards. Although the Administration has proposed to increase funding for NIMH research training, from $19.1 million in FY 1988 to $19.949 million in FY 1989, this proposal still is inadequate to ensure sufficient numbers of behavioral and biomedical scientists trained in mental health research.

The rate at which behavioral and biomedical scientists are being trained must be accelerated to keep pace with the exciting developments taking place in the mental health research field. Yet, exactly the reverse trend has occurred; the number of research trainees supported by NIMH has steadily declined by nearly 40 percent from a high of 1,348 trainees in FY 1980 to 837 trainees in FY 1988. Under the President's budget, only 837 research trainees would be supported in FY 1989. Even more alarming, research training funds as a proportion of total NIMH research funds have dropped from 13 percent in FY 1981 to only 7 percent in FY 1988.

In its 1985 report, "Personnel Needs and Training for Biomedical and Behavioral Research", the IOM strongly urged that research training funding be increased to attract more talented mental health professionals to research careers. The IOM specifically recommended increased federal support at the predoctoral level in behavioral research.

APA also recommends that the FY 1989 NIAAA and NIDA research training budgets be increased to $3.9 million and $2.9 million respectfully. The Administration's budget figures of $2.7 million and $2.4 million for the respective NIAAA and NIDA research training budgets are woefully inadequate to stimulate the production of highly qualified scientists trained in the areas of alcohol and drug abuse. We believe that training efforts must be intensified if our nation is to take advantage of current knowledge and make new inroads into the clearly pressing national problems of substance abuse.

APA's FY 1988 funding recommendations for other critical programs administered by ADAMHA are summarized (due to space limitations) as follows:

o NIMH Clinical Training	$26 million
o NIDA/NIAAA Homeless Demonstration Project Grants	$15 million
o NIMH Community Mental Health Services Block Grant	$100 million
o NIMH Community Mental Health Services Demonstration Projects	$40.4 million

STATEMENT OF MELVIN SABSHIN, M.D., MEDICAL DIRECTOR, AMERICAN PSYCHIATRIC ASSOCIATION

Senator DOMENICI. Dr. Sabshin from the American Psychiatric Association, we welcome you.

Dr. SABSHIN. Thank you, Senator Domenici. I am speaking today for the American Psychiatric Association and several other psychiatric groups and I am particularly delighted with the fact that there is an interaction between professionals, consumers, and citizens while that movement is developing. I thank your committee for its good judgment, foresight, and prudence in recognizing that the time has come for greater support for this field, the good judgment in seeing the opportunities, seeing that a threshold has been crossed.

The National Academy of Science and the Institute of Medicine have independently come to the same conclusion and indicated this is a time in our history where investment in these fields is quite prudent.

The fact that mental illness, alcoholism, and drug abuse costs $1,000 for every man, woman, and child in this country is a monumental factor in that we spend $1.80 per the same persons for research. It is grossly inadequate. And for long-range planning, vis-a-vis the budget issues you mentioned earlier, Senator, there ought to be a way to see that, as the costs reduce, that the country can save as long as we are sure about the developments in the field.

I am very pleased with the fact that now we have three directors in the ADAMHA program that are first-rate people, and with the advent of Dr. Judd onboard we have someone who symbolizes the excellence in the field and that is marvelous continuity there.

This committee's commitment to the national plan for schizophrenia and the decay of the brain laid out an important terrain.

It is well thought out and I hope will be implemented with your continued support.

There is a need of support, research on AIDS within the National Institute for Mental Health also with that balance portfolio in understanding that AIDS dementia is also an important national problem.

The infrastructure for research needs buttressing. The support for research training is obvious to develop the next generation of the cadre of people who can work here, for an infrastructure of instrumentation. A parallel to what happens at the NIH ought to be developed within the NIMH so that the necessary instruments can be funded to carry out that research.

We also are recommending a level of $40 million in research appropriations. We recommend a balanced portfolio, a balance between the basic research and the behavioral research, and that needs to be carried out. We ask you to have confidence in the new leadership of the Institutes, at the NIMH, like Dr. Judd, and other people be given the flexibility to determine the best possible mix, a balanced portfolio.

PREPARED STATEMENT

Obviously they will be accountable to you, and you can see whether their choice in scientific variables for that research is adequate as you look even at a larger terrain. You have laid out the terrain. Let them make those decisions. Let the leadership help to determine that mix, and I believe they will meet your expectations.

Thank you very much.

[The statement follows:]

STATEMENT OF MELVIN SABSHIN

Mr. Chairman and Members of the Subcommittee, I am Dr. Melvin Sabshin, Medical Director of the American Psychiatric Association, a medical specialty society representing over 34,000 psychiatrists nationwide. In addition, I appear before you today on behalf of the American Association of Chairmen of Departments of Psychiatry, the American Association of Directors of Psychiatry Residency Training and the American Society of Adolescent Psychiatry. I would also like to associate the APA with the budget recommendations developed by a large and diverse coalition of citizen and professional organizations based on a professional assessment of each activity under the jurisdiction of the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). This alternative budget overview is appended to the end of my statment.

Mr. Chairman, my association certainly understands the stringent fiscal limitations under which you are operating as the result of deficit reduction measures enacted at the close of the First Session of this Congress. While sensitive to these constraints, we would caution Congress that federal activities targeted at the problems of mental and addictive disorders can not be put "on hold" pending resolution of the federal deficit in our country. The Institute of Medicine of the National Academy of Sciences has stated that the personal and social costs of mental illness and substance abuse disorders are comparable to those for heart disease and cancer. While the costs of these disorders amount to approximately $1,000 per year for every man, women and child in the U.S., we are dismayed that the federal commitment to research funds to ADAMHA to combat these disorders in FY 1988 is approximately $1.80. Mr. Chairman, the nation cannot afford such a de minimus investment in meeting the challenges to prevent and treat the ravaging effects of mental and addictive disorders. Therefore, we present to you today an alternative budget which makes a compelling case for a substantial investment in research, training and services. There is a dire need for the federal government to support cutting-edge biomedical and behavioral research programs and to train talented young clinical and basic scientists to meet the challenges of research in the 1990s and the coming century. With robust federal support we are confident that your support will yield new important insights into brain function and the processes underlying mental disease and ultimately provide new cost-effective ways to prevent and treat alcohol, drug abuse and mental illness.

The President's proposed FY 1989 budget for ADAMHA will significantly reduce even the current scope of research, threatening the stability of funding for ongoing research and jeopardizing future investigation. The promise of the major National Plan for Schizophenia Research and the plan to implement the "Decade of the Brain" would be stalled in their tracks. Talented young investigators would be dissauded from engaging in research careers, slowing the quest for new knowledge and the search for tools to conquer the devastating human tragedies of mental illnesses and substance abuse.

Under the President's budget, NIMH, NIDA, and NIAAA would each be forced to reduce commitments to Clinical Research Centers, multidisciplinary centers of research excellence which are important in the generation of young researchers. Virtually no new research career awards at the Institutes would be awarded, an important concern for research infrastructure. Total research project awards would drop by 29 at the NIMH and by 53 at the NIDA. The infusion of funds to combat drug abuse would be halted after only a single year. Only 30 percent of approved NIAAA research projects would be able to be funded.

In comparison, the alternative budget which APA and the coalition submit to you would:

- o allow the NIDA to award 279 new and competing project grants of significant merit, including initiatives on new pharmacotherapies and on factors affecting vulnerability to drug abuse, enabling the Institute to continue funding high-quality grants consistent with the declared "war on drugs."
- o permit NIAAA to increase its new and competing awards by 30 over the FY 1988 level to 134 new and competing investigator-initiated project grants at IRG recommended levels, and to increase by 10 percent the overall number of research project grants supported by the Institute and to undertake an initiative to identify the genes influencing susceptibility to alcoholism and its sequelae.
- o facilitate the Institutes' capacity to support instrumentation and facility renovation needs of both the extramural and intramural research programs to improve the seriously deteriorating state of the apparatus needed to conduct biomedical and behavioral research in the 1980s and beyond.
- o allow each of the Institutes to expand further its Clinical Research Centers programs, critical sites of both research excellence and research training.
- o broaden the capacity to encourage young future researchers to the field through research career development awards funded under the research line item and through the NRSA research training program. NIMH alone could support 60 new RSDA awards with these funds, while the President's budget permits no growth. NIAAA could support an increase of 43 NRSA fellows or trainees over the FY 1988 appropriation; NIDA could support 10 new Research Scientist Development Awards.

Mr. Chairman, the long-awaited National Plan for Schizophrenia Research, and the "Decade of the Brain" plan for the neurosciences are two unique, important and exciting initiatives which must receive start-up support in FY'89. The challenge of schizophrenia to the psychiatric research community is not new. However, the opportunities for meeting it are new indeed—emerging from a fortuitous blend of new understanding and new hypotheses, the growing armamentarium of scientific technologies to test them, and a renewed commitment by the NIMH through adoption and proposed implementation of a National Plan for Schizophrenia Research.

The NIMH plan represents a convergence of opinion of scientists from fields predominately outside those centering on schizophrenia and sets forth a structured set of priorities and directions for this important research undertaking, an undertaking that will affect not only the future character of schizophrenia research, but also the quality and strength of research into other serious mental illnesses.

In its 1987 Committee Report the House Appropriations Committee directed NIMH's Advisory Council to submit a report to Congress "to establish a framework in which a multi-year effort can be made to capitalize upon the substantial growth in fundamental knowledge in the neurosciences which has occurred in recent years." The report projects "quantum leaps" in more basic research in brain development, learning and memory processes, neuron function in normal behavior, neuron function in producing emotions and cognition, and more. Like the schizophrenia research plan, this new ambitious plan calls for dramatic increases in funding. We applaud the Congress for assigning the high priority to neuroscience research on mental illness it deserves. It remains now to put funds behind this rich agenda of research.

This ambitious research agenda I have outlined can be acted upon only if adequate and stable resources are available, including personnel, facilities and equipment. The critical need for new psychiatrist-researchers is well demonstrated by the data that underscore the small numbers of physician-researchers being trained. The development of new independent investigators through research training and career development occurs over a decade or more. Those young researchers who enter the training pipeline today are being prepared to meet the challenges of biomedical and behavioral research in the 1990s and the coming century. ADAMHA must be able to enhance research training programs (under both the research training line item and the career development programs) and to imbue the funding picture with a sense of stability. Without such improvements, the current shortage of physician-scientists dedicated to research into aging, alcoholism, schizophrenia, affective disorders, disorders of children and adolescents, intravenous drug abuse, and other major disorders will grow more serious at the very moment the field is rife with scientific excitement.

In the past, research on mental illness and addictive disorders was not thought to require a sizable investment in either research equipment or facilities. Today, that assumption is clearly no longer valid. The tools essential for contemporary research range from costly PET and MRI apparatus to smaller items required for the operation of biomedical research laboratories. Gamma counters increase productivity in receptor research; video-enhanced microscopy permits better visualization. Video equipment enhances our capacity to study human behavior and development. Unfortunately, today, ADAMHA researchers have no federally-supported means of obtaining research instrumentation in the $5,000 to $100,000 range, and this is hindering progress in these fields. We urge the Committee to establish through report language eligibility for ADAMHA researchers for the NIH's Small Instruments Program.

Mr. Chairman, the field is confident that we can deliver our promises and save this nation far more in regained human productivity than the initial modest research investment. With adequate funding, we are confident that the research supported by ADAMHA will be able to:

- Build on the identification of genetic linkage markers associated with manic depressive illness, schizophrenia, and panic disorder by localizing precise genes and gaining an understanding of the actual physiological process encoded by the genes, providing the key to the development of more effective therapeutic interventions.
- Identify clinically needed biochemical markers and, ultimately, specific genes that influence susceptability to alcoholism.
- Apply what is understood of the pathophysiology of mental disorders to the design of site-specific drugs that intervene in disease states selectively, avoiding disturbing and sometimes disabling side effects. These new interventions should extend relief to patients who currently are treatment resistant.
- Improve screening and diagnostic instruments for Alzheimer's disease, thus permitting early intervention to slow the progress of this degenerative brain disorder through non-pharmacologic as well as new drug interventions.
- Elucidate the impact of alcohol on the immune system and its role as a possible cofactor in the transmission of HIV and the progression of AIDS.

This is only a short list of potential important breakthroughs which will translate into improved therapeutic interventions.

In the area of AIDS research supported by NIMH, we feel that the Institute Director should be free to exercise judgement as to allocation of research resources across the gamut of behavioral, virological, neurobiological and neuropsychiatric studies. In addition to the critical Institute role in examining the behavioral aspects of HIV infection, the organic complications are germane to the NIMH mission. These include central nervous system complications, including depression, a range of dementias, and cognitive and memory dysfuctions. We caution the Committee against micromanaging the Institute's AIDS portfolio and assigning an arbitrary precentage to each area of investigation.

Mr. Chairman, of course there are other important activities supported by and through the ADAMHA which are integral components of the federal arsenal to combat mental and addictive disorders. The table at the end of this statement outlines our funding recommendations for these activities—each based on the professional judgement of experts in the field. While the Committee's hearing time and space limitations upon public witnesses prevent me from articulating this in-depth, I assure you the justifications for these activities are solid.

These include the NIMH Clinical Training Program which continues to be a major source of training support for mental health professionals primarily in the fields of psychiatry, psychology, social work, and nursing. Our proposed alternative NIMH funding level would enable the program to support the recruitment, training and placement of mental health service providers in shortage areas consistent with the goals of the Institute and the needs of the nation. The proposed increase we suggest would enable the clinical training program to address Congressional mandates to focus attention on building a cadre of providers equipped to address the mental health needs of ethnic minorities; the long-term seriously mentally ill, (specifically those suffering from schizophrenia and major mood disorders); and other priority populations such as children and adolescents and the elderly. In addition, this modest increase in proposed funding levels would permit the clinical training program to foster training efforts oriented to the needs of public mental health services.

We also call to your attention our funding proposals for the important NIMH Services Demonstrations, Homeless Initatives, Planning Grants, Protection and Advocacy and for ADAMHA's critical services activities including the Block Grant. Support for the activities have reached dangerously low levels and I asked for your favorable consideration of our appropriations recommendations.

Mr. Chairman, thank you for this opportunity to appear before you and I would be pleased to answer any questions.

Senator DOMENICI. Thank you very much. Let me indicate that I, too, am very pleased with reference to the $400 million research request and the long-term plan on schizophrenia research, that we have citizen groups joined together with those who deliver. I think this is historic first with reference to them all coming together and supporting a cause.

With reference to the practicing psychiatrists—I assume that is what the American Psychiatric Association is—do I gather correctly that they, too, as a group, nationally support this effort? If such is the case, what has happened in the last 4 or 5 years to cause this unifying of effort with reference to seeking this very enhanced research budget?

Dr. SABSHIN. I would say, Senator, that the major force that is unifying us is the excitement about the new research. It is much more promising, really, than ever before and it begins to lay a pattern for us to be somewhat more hopeful.

Also, I think the stronger developments in the consumer movement, the citizens' movements, have given force to us, have helped to propel professionals in a new way and within the professional groups I think the new generation is very promising. They see what the high side of the mountain may be and they are ready to look across the next bridge.

Senator DOMENICI. Good morning, Senator Hatfield. How are you? We have a witness you want to talk to and we will call him up here shortly.

Dr. Sabshin, is instrumentation with reference to diagnosis on some new threshold that causes us to have a bit more enthusiasm on some new kind of basic information on the brain and its functioning? If so, is there a need for making sure that we fund instrumentation for the NIH in some of these very special areas?

Dr. SABSHIN. I will address that. My colleagues may wish to, also. I will comment, Senator Domenici, that at the NIH there are mechanisms with support for small instrumentation. And that is part of the infrastructure that I mentioned.

And, yes, there are a variety of new instruments, everything from the large scanning operations with the new list of human functions of both normal and very abnormal functioning, which is one of the most exciting developments, but in addition to those macrosystems, there are all sorts of microsystems that people have at their desks and in their laboratories, and that is what is needed to maintain the research.

Mr. HOWE. Senator, if I could add just a word. A few years ago we at the national alliance used to pound on the NIMH to do more serious research on the brain to try to learn what was causing the severe mental illnesses, and with respect to illnesses such as schizophrenia, a number of people said we don't have good ideas and money won't get you good ideas.

Within the past couple of years they have brought together between 70 and 80 of America's leading scientists, not just people in the field of schizophrenia, but people who had made success in other fields and they have had a lot of good ideas, so that when they gave us the national plan for the schizophrenia initiative, they cited three things which make this very timely.

One is we have a lot of good ideas for research. The second one is we have some technology now for testing those ideas. We are looking into the brain in nonintrusive ways to test whether these ideas work out or not and then, third, they mention what you have mentioned, that the great coalition of citizens, consumers, of families and of professionals have come together in an effective way.

Mr. LIPSITT. I would just like to add, sir, that many of the breakthroughs that have occurred, have occurred within just the past 3 years. One of our number said this morning that perhaps 90 percent of what we know about brain and behavior has really been learned in the past 5 years, and I think that that is a correct characterization.

I believe that it is fair to say that we, those of us who are studying brain and behavior, are on the threshold of some remarkable new discoveries. I know that that is rather a bold and, perhaps, overly heroic thing to say, but I really think, and many of my colleagues believe, that we are at the threshold of a new era of breakthroughs within the field of research that has to do with the origins, the precursors, of mental illnesses and behavior disorders.

I would just add, very briefly, that some of the technology that is coming forth today does not have to do with electronics so much as it has to do with psychometrics. It has to do with our increasing ability to detect subtleties of behavior that are relevant to mental disorders that are the precursors of mental disorders.

We need increasingly to study those antecedents that exist in people's lives for risk-taking behavior and other kinds of patterns of behavior that lead them into mental disorders and lead them into other kinds of behavioral misadventures; accidents, suicide, dangerous sexual behavior, drug taking, and so on.

Senator DOMENICI. Thank you very much. I just want to close this part of the record by indicating that in the event you as proponents are unaware, when Dr. Judd appeared before the subcommittee, he indicated that the national plan for schizophrenia research could effectively use $58 million in this year of implementation.

That number would be included, as I understand it, within the $400 million that is recommended by the combined group of professionals and citizen groups as they testified today. You have in mind, I assume, that we would like to start down that long-term road at about that level, is that correct?

Dr. SABSHIN. Yes.

Senator DOMENICI. Thank you very much.

Senator Hatfield, did you have any questions of these witnesses? Thank you very much.

John C. Crabbe, Jr., Ph.D., the Department of Medical Psychology, Oregon Health Sciences University. Would you please take the table and testify? We are delighted to have you.

Senator Hatfield, I understand you would like to, perhaps, inquire of this witness.

Senator HATFIELD. I thank the chairman for permitting me to introduce a fellow Oregonian and a person who has distinguished himself in the area of alcohol as the No. 1 drug problem of this country.

Mr. Chairman, I would like to make one brief comment and then listen to Dr. Crabbe's testimony. As former chairman of the Budget

Committee and now a member of the Appropriations Committee, Senator Domenici has had a long interest in medical matters and research. In fact, he joined me one time in Portland, not too many years ago, when we had a public hearing there and, Senator, I think that was one of the highlights in this committee's activity in terms of gathering public witnesses.

About and 2 years ago we became very much aware of the AIDS problem and we appropriated about $300 million at that time for AIDS research. That grew last year to $600 million. This year it is $900 million. Next year $1.2 billion for AIDS research and education. And I have been very supportive, and Senator Domenici has been very supportive, of all of those increases.

By the same token, I don't think we can ignore the ongoing problems that we have in other areas of medical research, and alcoholism is certainly one of them. Today, we are talking about trying to hold a 1988 level of $115 million in Federal grants and research in light of a budget request of $108 million for fiscal year 1989, when actually we should be talking about increasing that amount.

In our involvement with cocaine and other drugs, we realize that they are international in complexity as far as dealing with the problem. We are not dealing with just our country. But in alcoholism we are dealing with primarily a drug that emanates out of the processers' world in America. And I don't think that even the estimate of $117 billion for the social impact on this country is really anywhere near the cost factor.

If you go into the prisons of our country you will find that so much crime is alcohol related. If you go into mental health institutions, many problems are alcohol related. You could go on and on.

I am not sure that we really could put a finger on the total cost, and so I only want to say that as we are concerned about AIDS, and we should be, let us not neglect these other areas, ongoing areas of neurology and cardiology and areas like Alzheimer's research. We have so many battlefronts that we are on, we cannot neglect one point to try to bolster up another point.

STATEMENT OF JOHN C. CRABBE, JR., PH.D., DEPARTMENT OF MEDICAL PSYCHOLOGY, OREGON HEALTH SCIENCES UNIVERSITY

Senator HATFIELD I appreciate very much the opportunity to make this general comment in introducing Dr. Crabbe, Senator Domenici.

Senator DOMENICI. Thank you very much, Senator Hatfield.

Please proceed.

Mr. CRABBE. Thank you. I am John C. Crabbe, Jr., a professor of medical psychology and pharmacology at the School of Medicine at the Oregon Health Sciences University in Portland, and I am appearing today as a member of the Research Society on Alcoholism. Thank you for allowing me to appear.

The extent of the problems facing this country as a result of alcohol abuse and alcoholism is truly staggering. Senator Hatfield just mentioned that health care related and other social costs dealing with this problem is estimated by the Secretary of HHS at $117 billion in 1983, but all of the indications that we have are that this number has certainly not declined in the intervening 5 years. There is a massive social cost.

Nonetheless, the past few years have seen major progress on several research points, one of which, because of my involvement, I would like to confine my comments to today.

Alcohol research scientists have recently developed genetic animal models for several different aspects of abnormal biochemical and behavioral responsiveness to alcohol. The studies with these animals have identified neurotransmitters that derange metabolism in critical areas of the brain.

Other experiments have identified the influence of single genes on alcohol drinking and on alcohol withdrawal in experimental animals.

If the existence of similar genes can be verified in humans, we may be on the verge of taking a step further to the very important goal of identifying a clear individual genetic risk for susceptibility to alcoholism.

There are many other research advances in both human alcohol research and animal model systems. The studies of genetic factors in animals and humans which I mentioned are time consuming and tedious, for those studies must continue across many generations. This requires a sustained level of support from the Government for the momentum that we have begun to build or this attack on alcoholism is certain to be lost.

The President's fiscal year 1989 request for NIAAA provides $83.1 million for research, which will require a reduction in the number of new and renewal research grants, as well as cuts in the budget of all ongoing grants and, perhaps most critical, I think it will reduce the number of trained physicians available for young scientists.

A very encouraging recent trend has been the ability of the alcoholism field to attract young scientists at the beginning of their careers, for their commitment to alcoholism research will be lifelong. Such rejuvenation is the life's blood of any research area, and it would be a terrible mistake to stifle it.

The consequences of alcoholism will continue to consume an increasing proportion of the Federal budget until we can slow the progress of this devastating disorder.

PREPARED STATEMENT

The extra $19 million for research that we are seeking over the President's request is modest but I believe a critically necessary investment in our ability to control this $117 billion cost of alcoholism. The recent research advances I have outlined suggest that we are making substantial progress in understanding the disorder, and I hope that I have helped to convince you that such progress needs to be sustained.

Thank you.

Senator **Domenici**. Thank you very much. Your statement will be made a part of the record.

Did you have anything further, Senator?

Senator **Hatfield**. No.

Senator **Domenici**. We thank you very much for taking the time to come and join us today.

[The statement follows:]

STATEMENT OF JOHN C. CRABBE, JR.

I am John C. Crabbe, Jr., Professor of Medical Psychology and Pharmacology at the School of Medicine, Oregon Health Sciences University, Portland, Oregon. I am a member of the Research Society on Alcoholism. Among my immediate colleagues in Oregon I count several investigators involved in basic research on alcoholism and training of graduate and medical students for careers in combatting alcoholism, and I speak on their behalf as well. I thank the subcommittee members for allowing me to appear before them today.

The extent of the problems facing this country as a result of alcohol abuse and alcoholism is truly staggering. Fully 10-15 percent of the adult male population of the US is currently diagnosed as alcoholic, and at least half that percentage of adult women. The health care related and other social costs of dealing with this problem was estimated by the Secretary of HHS to be $117 billion in 1983, and we may be quite certain that it has not declined in the five intervening years.

The allocation of federal funds to combat alcoholism, which comes almost entirely through NIAAA, is vanishingly small. The current research budget for this institute is only 1.5% of the total funds allocated to NIH and ADAMHA. Yet, in spite of this discouragingly small level of support, the past few years have seen major progress on several research fronts.

1) There have recently been developed genetic animal models for several different aspects of abnormal alcohol-seeking behavior and abnormal biochemical and behavioral responsiveness to alcohol. Studies with these animals have identified that the neurotransmitter serotonin may have deranged metabolism in critical areas of the brain. Other experiments have identified the influence of single genes on alcohol drinking and on alcohol withdrawal in animals. If the existence of similar genes can be verified in humans, we may be a step further toward the important goal of identifying a clear genetic marker of risk for alcoholism.

2) Several years ago, it became clear that alcoholism was a highly heritable disorder, for the risk of first degree relatives of an alcoholic for themselves developing the disorder is 4-8 fold higher. Very recent research has begun to clarify the nature of that risk considerably. We have found that there are two etiologically distinct forms of alcoholism. While each is

inherited, the pattern of modulating environmental influences is different. Such information will be critical for the design of maximally effective prevention and treatment strategies.

3) Recent studies have demonstrated the presence of electrophysiological markers that reveal unusual brain wave patterns in children of alcoholics that differentiate them from children of non-alcoholics. This research, too, offers a possible means of non-invasively identifying individuals at increased risk at an age where preventive interventions may be helpful.

4) Molecular biological studies have allowed us to detect individual differences in the enzymes ADH and ALDH, which control alcohol metabolism. Patterns of family inheritance of these genes are now allowing us to compare animal and human genetic models closely.

There are many other advances, with both human alcoholics and animal model systems. I have commented on the ~~genetic~~ advances because I have been developing genetic animal models during the last 10 years and am very excited about the prospects for beginning to apply the animal work to the human situation. The study of genetic factors in animals or humans, is a time-consuming and tedious undertaking, for such studies must continue across many generations. This requires a sustained level of support from the government, or the momentum we have begun to build in the attack on alcoholism will be lost.

The President's FY1989 request for NIAAA provides only $108.2 million, of which $83.1 million would be for research. Current allocations are estimated at $115.4 and $87.7 million, respectively. Thus, the President's budget will require a reduction in the number of new and competing renewal grants, as well as cuts in the budgets of ongoing grants. Perhaps most critically in my view, it will reduce the number of training positions available for young scientists. One of the most encouraging recent trends has been the ability of the alcoholism field to begin to attract young scientists at the beginning of their careers, where there commitment to alcoholism research will be lifelong. Such constant rejuvenation is the life's blood of any research area, and it would be a terrible mistake to stifle it at this stage.

The Research Society on Alcoholism, the American Psychiatric Association, the American Psychological Association, and other relevant groups are recommending an F&89 budget for NIAAA of $148.8 million and 231 FTEs. This represents an increase of $40.6 million and 36 FTEs over the Administration's request. Of this, $102.1 million would be for research. The additional FTEs are to alleviate a serious understaffing in intramural research and direct operations. The additional dollars will increase the number of research project grants from 328 to 359; provide $5.4 million for a major genetics initiative to identify the genes responsible for alcoholism; provide full funding for the Alcohol Research Centers; provide support for 159 research trainees; and provide some long overdue funds for instrumentation and renovation projects.

Certainly, one cannot manage the federal budget by increasing expenditures in every category. Just as certainly, the problems and consequences of alcoholism will continue to consume a increasing proportion of that budget until we can slow the progress of this devastating disorder. In my opinion, the extra $40.6 million we are seeking over the President's request is a modest, but critically necessary, investment in our ability to control the $117 billion cost of alcoholism. The recent research advances I have outlined suggest that we are making substantial progress in understanding the disorder, and I hope that I have helped to convince you that such progress needs to be sustained.

Thank you

STATEMENT OF JOHN C. LINTON, PH.D., DEPARTMENT OF BEHAVIORAL SCIENCE, WEST VIRGINIA UNIVERSITY SCHOOL OF MEDICINE, CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Senator DOMENICI. Our next witness is John C. Linton, Ph.D., Department of Behavioral Science, West Virginia University School of Medicine, Consortium of Social Science Associations.

Doctor, we welcome you and please proceed and your statement will be made a part of the record.

Mr. LINTON. Mr. Chairman and members of the subcommittee and staff, I am John C. Linton, professor, Department of Behavioral Medicine, West Virginia University School of Medicine.

I speak this morning on behalf of the Consortium of Social Science Associations and the American Psychological Association. My testimony will focus on appropriations for the National Institutes of Health and specifically the need to increase the proportional funding for research on health and behavior.

In response to evidence that developments in many fields of biobehavioral sciences have great potential for improving the diagnosis, prevention, and treatment of illness, in recent years this subcommittee has directed NIH to increase its support for health and behavior research and to report back to Congress on its progress in this regard.

I would like to commend you, Mr. Chairman, and the subcommittee, for your continued support for NIH-funded research on the realm of behavioral and social influences and health promotion and disease prevention.

In this year's health and behavior report to Congress, NIH indicates that in fiscal year 1987 it spent 2.8 percent of its budget on health and behavioral research and research training. Although this is a significant increase over previous years' funding, the proportion of the overall NIH budget devoted to the health and behavior research agenda has remained relatively constant in recent years at 3 percent of the total NIH budget.

As the Nation's largest source of funding for basic research on health and disease, NIH has a special responsibility to heed the findings of the Institute of Medicine's report entitled "Health and Behavior, A Research Agenda" which NIH cosponsored.

This report identified lifestyle and behavioral factors as the major causes of death in the United States. It has also become clear that the most significant way to reduce the AIDS pandemic is to educate people on changing behaviors and lifestyles. NIH is to be commended for its health and behavior work in these areas, but more resources are needed.

We, therefore, recommend that NIH establish each year meaningful and explicit goals to raise its expenditures for health and behavior research from its current proportion of 3 percent to a target level of 10 percent.

Additionally we recommend a substantial increase in the number of NIH-supported research trainees. We urge the subcommittee to provide research training funds sufficient to enable NIH to specifically enhance research training opportunities for behavioral scientists. We also urge your continued support in the Biomedical Research Support Grant Program and other mechanisms to further the support of new investigators, innovative research projects, and techniques in multidisciplinary research.

The National Institute on Aging and the National Institute on Child Health and Human Development are the key Institutes supporting social and behavioral research as it relates to health. We support the continued overall fiscal health of these two institutes.

Recently the NIA Advisory Council endorsed the recommendation of the ad hoc advisory panel to the NIA Behavioral and Social Research Program on priorities for data collection and health and retirement economics. This panel, chaired by Dr. Jim Smith of the Rand Corp., makes a strong case for the improvement of data on the economics of aging. It concluded, and I quote, "The scope and quality of current data are placing unnecessary limits on advances in aging research."

One of their major recommendations was to seek support for a new longitudinal survey on retirement and health. We ask that the subcommittee lend its support to such an effort.

The National Institute of Child Health and Human Development is the major source of Federal funding for research pertaining to maternal and child health and population sciences. It is about to conduct a new survey on adult sexual behavior, the first comprehensive evaluation since the Kinsey report over 40 years ago.

This survey will provide information as to the current sexual practices of the general population, the use of contraceptives, and the sexual behavior of at-risk populations for sexually transmitted diseases. The results of that survey can be used for developing programs to deal with the behavior of those susceptible to AIDS.

We urge the subcommittee to direct the National Cancer Institute that it dedicate a larger proportion of its budget to behavioral research, particularly in the area of cancer prevention. NCI indicated in its component of the NIH "Health and Behavior" report that smoking and tobacco use, diet nutrition, and regular cancer screening, all behavioral factors, are critical to cancer control.

Clearly increased attention to biobehavioral research and human behavior is an important step in order for NCI to meet its goal of reducing our Nation's annual cancer death rate by 50 percent by the year 2000.

Finally, we recommend that the National Heart, Lung, and Blood Institute be directed to increase significantly its percentage of funds dedicated to behavioral research.

Fifty-five percent of all deaths in 1986 are accounted for by cardiovascular, lung, and blood diseases. These diseases represent 5 of the 10 leading causes of death and are alone responsible for 24 percent of the total economic costs of all illnesses and premature deaths.

PREPARED STATEMENT

Nowhere is the relationship between health and behavior clearer than in coronary, lung, and blood diseases. Heart, lung, and blood has done excellent work in this area, and we urge that an increased proportion of its fund be dedicated to this important behavioral research.

Thank you for the opportunity to present our views.

Senator DOMENICI. Thank you. Your statement will be made a part of the record.

[The statement follows:]

STATEMENT OF JOHN C. LINTON

Mr. Chairman and Members of the Subcommittee: I am John C. Linton, Professor, Department of Behavioral Medicine, West Virginia University School of Medicine. I speak this morning on behalf of the Consortium of Social Science Associations (COSSA) and the American Psychological Association (APA). COSSA represents over 185,000 American scientists across the broad range of social and behavioral science disciplines. A list of COSSA Members, Affiliates and Contributors is attached to this testimony. APA is a scientific and professional organization representing 90,000 psychologists in the United States.

My testimony will focus on appropriations for the National Institutes of Health (NIH) and specifically the need to increase NIH funding for research on health and behavior. In this year's report to Congress, required by this Subcommittee's continued interest, for which COSSA commends you, NIH indicates that in FY 1987 it spent $179 million, or 2.8 percent of its $6.2 billion budget, on health and behavior research and research training. Although this is a significant increase over previous years' funding, the proportion of the overall NIH budget devoted to the health and behavior research agenda has remained relatively constant in recent years at 3 percent of the total NIH budget. We recommend that NIH establish each year meaningful and explicit goals to raise its expenditures on health and behavior research from its current proportion of three percent to a target level of ten percent.

As the nation's largest source of funding for basic research on health and disease, NIH has a special responsibility to heed the findings of the Institute of Medicine's (IOM) conference and its report Health and Behavior: A Research Agenda, which NIH cosponsored. The IOM report noted: "The burden of illness has shifted from acute infectious diseases to chronic diseases with multiple interacting risk factors, which prominently include such behavioral elements as smoking, alcohol, exercise, diet and response to stress." The IOM report also identified lifestyle and behavioral factors as the major causes of death in the U.S.

NIH has reacted to this problem by establishing a Working Group on Health and Behavior. This group, which includes representatives of all the institutes, has developed the following statement on health and behavior research:

> Many medical problems, including heart disease and cancer, appear to be influenced by behavioral and social variables, such as habits of living; by social environments (work, family, community); and by what has been termed psychosocial stress. A wide range of NIH-supported studies deals with three types of processes linking behavior to physical illness: (1) health impairing habits and lifestyles, such as smoking, heavy drinking, lack of exercise, poor diet, and poor hygienic practices; (2) reactions to illness, including minimizing the significance of symptoms, delay in seeking medical care, and failure to comply with treatment and rehabilitation regimens; and (3) direct alterations in tissue function through the brain's influence on hormone production and other physiological responses to psychosocial stimuli, particularly stress.

Furthermore, it has become clear that the most significant way to reduce the AIDS pandemic is to educate people on changing behaviors and lifestyles. NIH is to be commended for creating the Working Group, but more resources are needed.

In addition, we recommend a substantial increase in the number of NIH-supported research trainees. The IOM report specifically called for increased federal support in behavioral research training. We urge the Subcommittee to provide research training funds sufficient to enable NIH to specifically enhance research training opportunities for behavioral scientists. We also urge your continued support for the Biomedical Research Support Grant Program and other mechanisms to further the support of new investigators, innovative research projects and techniques, and multi-disciplinary research.

The National Institute on Aging (NIA) and the National Institute on Child Health and Human Development (NICHD) are the key institutes supporting social and behavioral research as it relates to health. We support the continued overall fiscal health of these two institutes.

NIA, in particular, has developed a health and behavior agenda that needs increased support. Planning is underway for an initiative on human factors and aging. Further research is necessary to identify age-related differences in the ability to concentrate and to divide attention. Basic epidemiological research needs support to gain wider knowledge of the interacting biomedical, social and behavioral risk factors for injuries, associated morbidities, and the need for health care.

Recently the NIA Advisory Council passed a motion to endorse the recommendations of the Report of the Ad Hoc Advisory Panel to the NIA Behavioral and Social Research Program on Priorities for Data Collection in Health and Retirement Economics. This panel, chaired by Dr. Jim Smith of the RAND Corporation, makes a strong case for the improvement of data sets on the economics of aging. It concluded: "The scope and quality of current data are placing unnecessary limits on advances in aging research." One of the major recommendations was to seek support for a new longitudinal survey on retirement and health. We ask that the Subcommittee lend its support to such an effort.

As the panel noted: "Because the well-being of aging Americans depends on both their health and their economic status, the lack of data files that combine good information about health with adequate economic measures is shameful." Some of the most important phenomena and questions about aging and well-being are being left unanswered. For example: How does financial status affect health status and health service utilization? Do the disabled elderly have sufficient wealth to purchase long-term care insurance? How do financial status and physical impairments affect living arrangements? Would declining levels of mental and physical functioning negate the benefits of a change in the mandatory retirement age? Clearly, economics play a powerful role in determining health in this country. To answer these questions we need adequate measures of both health and economic factors.

NICHD is the major source of federal funding for research pertaining to maternal and child health and population sciences. Its work on health and behavior is vitally important. It is about to conduct a new survey of adult sexual behavior (the first comprehensive evaluation since the Kinsey Report over forty years ago). This survey will provide information as to the current sexual practices of the general population, the use of contraceptives, and the sexual behavior of at-risk populations for sexually transmitted diseases. Results of the survey can be used for developing programs to deal with the behavior of those susceptible to AIDS. In addition, NICHD is conducting studies of the interrelationship of fertility, employment, and child care. This research will impact the health of women in the workplace and will affect many other issues of national concern.

We recommend continued support for the National Cancer Institute (NCI), and urge the Subcommittee to direct NCI to dedicate a larger proportion of its budget to behavioral research, particularly in the area of cancer prevention. NCI indicated in its component of the NIH report to the Committee on Appropriations, "Health and Behavior Research Initiatives by NIH, FY 1987," that smoking and tobacco use, diet and nutrition, and regular cancer screening, all behavioral factors, are critical to cancer control. Clearly increased attention to biobehavioral research and human behavior is an important step in order for NCI to meet its goal of reducing our Nation's annual cancer death rate by fifty percent by the year 2000.

We recommend that the National Heart, Lung and Blood Institute (NHLBI) be directed to increase significantly its percentage of funds dedicated to behavioral research. Fifty-five percent of all deaths in 1986 are accounted for by cardiovascular, lung, and blood diseases. These diseases represent five of the ten leading causes of death, and are alone responsible for twenty-four percent of the total economic costs of all illnesses and premature deaths. Nowhere is the relationship between health and behavior clearer than in coronary, lung, and blood diseases. NHLBI must increase its concern with this relationship.

Thank you for the opportunity to present our views.

STATEMENT OF WILLIAM L. DEWEY, PH.D., CHAIRMAN, COMMITTEE ON PROBLEMS OF DRUG DEPENDENCE

Senator DOMENICI. The next witness is William L. Dewey, Ph.D., chairman of the Committee on Problems of Drug Dependence.

Mr. DEWEY. Thank you, Mr. Chairman. I appreciate the opportunity to be here before you today. With me is Dr. Martin Adams, the executive officer of our organization. I am associate professor for research and graduate affairs at Virginia Commonwealth University, but I am appearing before you today as chairman of the Committee on Problems of Drug Dependence.

CPDD is the longest-standing scholarly society addressing the national problem of drug abuse in this country. We are represented by some 500,000 scientists and physicians who send representatives to our organization.

The activity of CPDD began in 1929 and has three major objectives. One is we run a testing facility for all new compounds, for their effect on the brain and dependence liability. Second, we run the major scientific meeting in the world in the area of drug abuse and, third, we are the resource of national and international organizations.

I am here today requesting that you appropriate sufficient funds to allow the excellent research that has been going on at the National Institute of Drug Abuse over a number of years to continue.

We are shocked and very disappointed that the administration has requested a decrease in the non-AIDS budget for NIDA for fiscal year 1989. This is at a time when drug abuse remains a major problem in our country.

To the best of our knowledge, NIDA is the only Institute that is being recommended for a decrease in budget. In fiscal year 1987 we appropriated sufficient funds to allow 538 research and training projects be carried out. With a 10-percent increase for fiscal year 1988, the number has decreased to 520 projects and with the administration's recommendation for fiscal year 1989 there will only be 461.

This is a 14-percent decrease in the amount of research that can be carried out in drug abuse. In addition, other projects which are underway will also be decreased to allow this to occur.

One might question why funds that are delegated or appropriated for drug abuse research will help the problem of drug abuse in society. The major issue is that drug abuse purely is a biomedical problem. Many agree that this biomedical problem, like any other biomedical problem, is going to be cured by taking chances through research and appropriate research.

Significant advances are being made in drug abuse research. We have made advances in prevention research and clearly, as you said earlier this morning yourself, prevention is the best way to cure these problems. That is the ideal.

NIDA supporting prevention research has resulted in a 50- to 75-percent short-term reduction in smoking in junior high school students. This should be expanded to other drugs of abuse and is being carried out in that regard right now.

Increasing the confidence levels of youngsters has been shown to help them resist peer pressure to become drug abusers.

In the area of treatment, we have a new drug, naltrexone, which is a pure narcotic antagonist which will cure the patient who overdoses on an opiate. This drug is being used widely and is saving lives today. Clonidine is a new drug that is being used to treat opiate withdrawal. Opiate morphine has just been approved to treat opiate withdrawal. Antidepressants are being used to treat cocaine intoxication.

So in summary what we are here to ask is that, in fact, the funding for drug abuse continue to occur. This not only helps drug abuse funds but it helps other areas, such as mental health, control of pain, respiratory diseases, and AIDS and others. I thank you for the opportunity to be here this morning.

Senator DOMENICI. Thank you very much. We will do our very best. We understand the problem just as you have explained it. Thank you very much.

[The statement follows:]

STATEMENT OF WILLIAM L. DEWEY

Mr. Chairman and Members of the Subcommittee, my name is William L. Dewey. I am Associate Provost for Research and Graduate Studies and Professor of Pharmacology at Virginia Commonwealth University in Richmond, Virginia.

I am speaking today as Chairman of the Committee on Problems of Drug Dependence, or CPDD.

CPDD, organized in 1929, is the longest standing scholarly society in the United States concerned with problems of drug abuse. Today CPDD is a distinguished multidisciplinary panel that is sponsored by ten professional medical and scientific societies, on which many of the most respected researchers in the area of drug abuse serve. The Committee has three principal functions. First, we test new chemical entities, marketed drugs and street drugs for government agencies, industry and academia to determine whether any such drugs have the potential to produce dependency or are prone to abuse. The Committee also holds what is generally regarded as the major annual meeting in the U.S. in the field of drug abuse. Finally, CPDD continuously contributes to public information and the public debate on issues relating to drug abuse and dependency by serving in a consultative capacity for local, national and international government agencies.

CPDD is very concerned about the Administration's request for a $4.5 million decrease for non-AIDS drug abuse research at the National Institute on Drug Abuse. NIDA is the only Institute in ADAMHA recommended for a reduction! This decrease is coming at a time when the last year's funding was not even sufficient to simply continue projects begun under the President's 1986 Drug Initiative. In fact, 20 fewer projects were funded this year. With the recommended FY 1989 budget, we estimate that only about 460 projects can be supported, a drop of 80 research grants and contracts in the last two years. We find this alarming. Continued stable funding is essential for NIDA grantees to continue making significant contributions, including expanding our knowledge of the functioning of the brain.

Basic research into the prevention and treatment of drug abuse and dependence is among the most critical needs of our time. The societal costs of drug abuse continue to mount at an alarming rate and the problems have reached every neighborhood in America. The costs of treating addiction mounts steadily as well. It has been estimated that the health costs of caring for addicts now exceed $50 billion. Yet the Administration proposes to cut back again on the only hope we have for reducing these costs -- research into prevention and treatment. Unless the Congress supports the basic research into the causes and treatment of drug abuse, I submit the nation will never bring the drug abuse problem under control.

NIDA-funded substance abuse prevention research shows great promise. Studies on the psycho-social factors involved in substance use are enabling us to understand better why our youth become substance abusers. Already several pilot programs have resulted in a 50-75% short-term decline in cigarette smoking among junior high students. A substantial effort must be expended to determine the long-term efficacy of these models. We must first understand why people are vulnerable and then reduce that vulnerability. An example of this principle is research ongoing to develop life/coping skills training to enhance the confidence and self esteem of the young. Preliminary reports indicate that student or family initiated and directed prevention programs may be very effective in helping young people resist peer pressure to become substance abusers. We must continue research to determine how best to maximize this important facet of prevention. Other research approaches the question of vulnerability by exploring whether certain persons are more predisposed biologically than others to substance abuse. Promising work has begun, for example, on the brain wave patterns of certain parents and their children which indicates a potential genetic pre-disposition to substance abuse.

The research exemplified above will help us prevent drug abuse, a far better alternative than being forced to treat it. Preventing drug abuse will also lessen transmission of AIDS by intravenous drug users. For this reason we urge this Committee to state emphatically to HHS that a fair portion of the funds to combat AIDS, which will be assigned as I understand it to the Assistant Secretary for Health, be allotted to drug abuse prevention research.

Since prevention will only come with time, we must be equally vigilant in conducting treatment research. That research is focusing on non-opioid problems, primarily the almost unchecked spread of cocaine abuse. Substance abuse is now recognized to be a multi-faceted syndrome where indiscriminate treatment is doomed to failure. Researchers have developed the Addiction Severity Index ("ASI") which permits the identification of subgroups with different problems. The use of the ASI has permitted therapists to assign patients to varying treatment programs with a greater likelihood of success. We have learned, for example, that people with a low rating on the index can be treated effectively on an outpatient basis. The ongoing research has also demonstrated that certain groups will not profit at all from the usual treatment programs. What began as a retrospective study has now progressed to the point where patients can prospectively be matched to a particular treatment program with the greatest likelihood of success. Much more work is needed and the payback is clear. More people will be more effectively treated at greatly reduced cost to the taxpayer, who ultimately pays for the reimbursement programs.

Other drug research is also paying off. Clonidine is now available. It reduces opioid withdrawal symptoms, making it easier for addicts to break their habit. Preliminary data shows it may do the same thing for smokers. This finding has led researchers to question whether there is a common neural pathway relating to withdrawal symptoms from any addictive substance, a subject deserving of further investigation. This must be explored.

Another new drug is Naltrexone, an opiate blocker used to treat post-addicts after detoxification. The compound blocks the effect of subsequent injections of an opiate. NIDA funds were instrumental in the development of this drug, which also is used as an antidote to narcotic overdose and has saved thousands of lives. The Federal Government must support this research. Pharmaceutical companies are reluctant to have their products associated with drug abuse. These compounds are just like orphan drugs.

In conclusion, prevention and treatment research in the field of drug abuse is helping us to understand many biological, psychological and societal factors that promote substance abuse. We are also focusing in on how to characterize patients for effective treatment. We are adding important new drugs to aid that treatment. These efforts all need to be continued. Substance abuse rivals heart disease, cancer and AIDS in its human and economic impact on our society. You need only pick up a newspaper or turn on a television set to be bombarded by news of the impact of drugs on us all. The non-AIDS NIDA research funds HHS has recommended are woefully inadequate to address these problems. We strongly support an increased appropriation for NIDA. Based on our analysis, a figure of $150 million for non-AIDS research would be sufficient to restore the research initiative begun in 1987 and would provide the resources for orderly growth.

I thank you for this opportunity to appear before you and for your outstanding leadership in the past in providing funding for research in this critical area.

STATEMENT OF LYNN P. REHM, PH.D., CHAIR, COUNCIL OF UNIVERSITY DIRECTORS OF CLINICAL PSYCHOLOGY

Senator DOMENICI. Lynn Rehm, chairman of the Council of University Directors of Clinical Psychology.

Mr. REHM. Thank you, Senator, members of the subcommittee and staff. I appreciate the opportunity to present testimony on the subject of the fiscal year 1989 appropriations for the National Institute of Mental Health's clinical training program.

My name is Lynn Rehm. I am a professor of psychology at the University of Houston, clinical psychologist, and I am chair of the Council of University Directors of Clinical Psychology, an organization that represents 135 clinical psychology doctoral programs in the United States.

My testimony this morning is also supported by the American Psychological Association, by the National Association of Social Workers, and by the American Association of Colleges of Nursing.

The Council of University Directors of Clinical Training strongly supports continued and increased funding at $26 million for NIMH clinical training activities in fiscal year 1989. This recommendation is also supported by the Mental Health Liaison Group, a coalition of more than 40 consumer, provider, professional, scientific, and citizen advocacy organizations.

The NIMH provides the major source of the Nation's mental health clinical training funds. The program has supported student trainees in psychology and the other three core mental health professions, psychiatry, social work, and psychiatric nursing, in every State. These trainees then become vital providers of mental health and health services in communities throughout the country.

My own experience in the University of Wisconsin, earlier at the University of Pittsburgh, as an NIMH training grantee, suggests to me that these programs have been effective in improving access to graduate education and priority mental health areas, have improved the quality of the experience and they have attracted students to work in priority areas.

Last year the Congress approved the first increase in funding for the NIMH clinical training program since 1979 by appropriating $16.8 million in fiscal year 1988 funds. We have appreciated your support and the wisdom of your efforts to redirect the clinical training program toward the training of mental health providers who can meet the needs of still underserved priority populations; the chronically mentally ill, children and youth with serious mental illness, the elderly with mental disorders, and minority and disadvantaged groups.

Demographic projections suggest that there will be a steady increase in the number of persons, particularly among the elderly and ethnic minority groups, suffering from schizophrenia and other serious mental disorders, multiple coexisting medical, and psychiatric conditions.

A recent NIMH conference held at the University of Houston stressed the importance for effective treatment of the chronically mentally ill in particular, not only of biological interventions—and I would like to stress that in recent years, yes, indeed, we have made breakthroughs and progress in that area.

There have also been breakthroughs in progress with regard to effective psychosocial interventions and most effective programs for the chronically mentally ill these days are programs which follow through with psychosocial, social learning, behavioral rehabilitative family services, et cetera, to maintain the chronically mentally ill patients out of hospitals in the community, et cetera.

It has also been documented that 3 million children and adolescents currently are in serious need of mental health services but only about 1 million receive needed treatment. Thus, while there have been substantial increases in the number of trained mental health professionals over the past two decades, it is very shortsighted to conclude that special efforts are no longer needed to address the Nation's mental health manpower needs in priority areas.

The council recommends increased emphasis on training toward underserved population groups and we certainly support the payback provision and program in the NIMH training program as an effective mechanism.

We also like to see equitable distribution of program funds among the core of mental health professions. Psychology, for example, supplies 30 to 40 percent of all trainees who incur a payback obligation for service-in-training priority areas but receives only about 10 percent of all clinical training funds.

PREPARED STATEMENT

A more equitable distribution of program funds would help to ensure that taxpayers receive the maximum return on their investment in this program.

My written testimony also supports very strongly the research training program and the minority mental health fellowship program, and I hope you would attend to those as well.

Thank you very much for the opportunity.

Senator DOMENICI. Thank you very much, Dr. Rehm.

[The statement follows:]

STATEMENT OF LYNN P. REHM

Mr. Chairman and Members of the Subcommittee, I appreciate this opportunity to present testimony on the subject of fiscal year 1989 appropriations for the National Institute of Mental Health (NIMH) clinical and research training programs. I am Dr. Lynn Rehm, a clinical psychologist on the faculty of the University of Houston, and in private practice. I am also Chair of the Council of University Directors of Clinical Psychology, an organization which represents over 80 percent of the approximately 170 clinical psychology programs in the United States. My testimony is supported by the American Psychological Association, the National Association of Social Workers, and the American Association of Colleges of Nursing.

NIMH Clinical Training Program

The Council of University Directors of Clinical Training opposes the request of the Reagan Administration to phase out the Clinical Training Program over a three-year period beginning in FY 1989. We strongly support continued and increased funding at $26 million for NIMH clinical training activities in FY 1989. This recommendation is also supported by the Mental Health Liaison Group - a coalition of more than 40 consumer, provider, professional, scientific, and citizen advocacy organizations.

The NIMH provides the major source of the nation's mental health clinical training funds. The program has supported trainees in psychology and the other three core mental health professions -- psychiatry, social work, and psychiatric nursing -- in every state, and provides critical support for the training of professionals who are properly equipped and skilled to provide mental health services to priority populations.

Congress has consistently rejected the Administration's efforts to eliminate the clinical training program over the past eight years. We have appreciated your support and the wisdom of your efforts to redirect the clinical training program toward the training of mental health providers who can meet the needs of still underserved priority populations: the chronically mentally ill, children and youth with serious mental illness, elderly with mental disorders, and minority and disadvantaged groups.

We believe that this redirection was not only appropriate but also is the best way to invest limited federal resources. Demographic projections suggest that there will be steady increases in the numbers of persons, particularly among the elderly and ethnic minority groups, suffering from schizophrenia and other serious mental disorders, and multiple coexisting medical and psychiatric conditions. Moreover, it has been documented that 3 million children and adolescents currently are in serious need of mental health services, but only about 1 million receive needed treatment. While there have been substantial increases in the numbers of trained mental health professionals over the past two decades, it would be very shortsighted to conclude special efforts are no longer needed to address the nation's mental health manpower needs.

Last year, Congress approved the first increase in funding for the NIMH clinical training program since 1979 by appropriating $16.8 million in FY 1988 funds. We applaud this increase in an era of severe budget constraint. Nonetheless, the current level of funding is 16 percent below what it was just two years ago, and there has not been a corresponding drop in the level of the nation's mental health needs.

For FY 1989 and beyond, the Council recommends increased emphasis on clinical training directed toward specific underserved population groups and underserved areas by expanding the number of student trainees who incur a service obligation, including those students supported through the Minority Fellowship Program. In our view, the single most effective mechanism for addressing the shortage of mental health professionals serving priority populations is the "payback" provision of the clinical training program. This statutory provision requires all trainees in psychology, psychiatry, social work and nursing who receive stipends for long-term graduate training (for a period of 180 days or more) to repay this direct support through service delivery in a mental health shortage area or with an underserved population. As of October 1987, nearly 2500 graduate mental health professionals in the four core mental health disciplines had practiced or will practice in public facilities with priority populations or perform some other acceptable public service.

To ensure further the accountability of the clinical training program, the Council recommends elimination of the payback exemption for short-term training, and equitable distribution of program funds among the four core mental health professions. Psychology, for example, supplies 30 to 40 percent of all trainees who incur a payback obligation for service in a priority area, but receives only about 10 percent of all clinical training funds. A more equitable distribution of program funds would help to ensure that taxpayers receive the maximum return on their investment in this program.

Research Training

The Council is concerned with adequate funding for the NIMH research training program in FY 1989. One of the unique aspects of the training of clinical psychologists is that our model for training integrates research and clinical skills. The result of such a training model is that the clinical psychologist is skilled in evaluation and quality of care issues as well as the delivery of services, and the research psychologist is prepared to study important clinical problems. The number of research trainees supported by NIMH has declined steadily over the past eight years from 1,173 trainees in FY 1981 to a projected low of 837 trainees in FY 1989. This consistent decrease in numbers of research trainees funded by NIMH will make it increasingly difficult to ensure an adequate supply of well trained mental health researchers who bring new "intellectual capital" to the field in the future. We recommend the appropriation of $26.2 million for NIMH research training.

Minority Fellowship Program

Finally, the Council encourages this Committee to continue its past strong support of the Minority Fellowship Program (MFP), which is designed to support the clinical and research training of ethnic minorities in mental health fields. The American Psychological Association (APA) has participated in the MFP since 1974 and APA's MFP has emerged as a national model of graduate training opportunities for ethnic minority psychologists. The program has been a wise investment, training 11 percent of all doctoral level ethnic minority psychologists providing health and mental services. Well over 200 Blacks, Hispanics, Native Americans, Asians and Pacific Islanders have received their doctoral degrees because of their participation in the APA MFP. Nevertheless, the need for far greater numbers is still evident in the underrepresentation of ethnic minorities in the field of psychology and the other core mental health disciplines. Fewer than 5 percent of all doctoral level psychologists providing health and mental health services are ethnic minorities.

Yet despite the MFP's highly successful track record, its federal funding has dropped from a high of $2.6 million in FY 1981 to only $2.2 million in FY 1988. We recommend that this Subcommittee include specific language in its report accompanying the FY 1989 appropriations bill to ensure that additional resources are devoted to this program.

Thank you for the opportunity to testify on behalf of the Council on NIMH clinical and research training appropriations.

STATEMENT OF JERRY M. WIENER, M.D., PRESIDENT, AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY

Senator **Domenici**. Dr. Wiener, president of the American Academy of Child and Adolescent Psychiatry.

Doctor, we welcome you once again. Nice to see you.

Dr. **Wiener**. Senator, thank you very much for the opportunity to appear before you. It is a pleasure to see you again, sir.

We have submitted our prepared remarks for the committee and, if I could, I would like to speak to you somewhat more informally and not affirm those remarks per se. I am president of the American Academy of Child and Adolescent Psychiatry, which is a group of 4,000 physicians trained in that particular subspecialty, and at the same time serve as chairman of the Department of Psychiatry at the George Washington University Medical Center here in the District of Columbia and have an opportunity to see the problems that I talk about with you in the field, as it were, as well as from an organizational point of view.

I want to reaffirm the support that has been expressed here previously for the $400 million budget in research, and in particular that is the cutting edge of any profession or scientific field and it is a particularly important and exciting area of activity in brain and behavior and in understanding the interaction between the two.

I speak for the particular interests in my capacity here for child and adolescent concerns, for the interests of children and adolescents who form the future of our country.

I am particularly heartened that the Congress has increasingly recognized the importance of the children and adolescents in programs, both in services and in research, for children and adolescents, and I think that there is an encouraging move, a direction and priority being given to those areas.

There are areas including research, including research training, including clinical training and services support, all of which deserve increasing support from the appropriations. In research, that has already been discussed.

Children and adolescents do need to have special attention. Nothing can be more important than understanding the origins, the developmental origins and the causes and the early prevention and early treatment of the mental illnesses and behavioral disorders of children and adolescents and those which are going to be the antecedents of adult disorders as well.

Without an increased budget for research training, we are not going to train the scientists to do the research in the future and I would urge an increase in the funding for research training.

It is a particular priority that Dr. Judd has established for the National Institute of Mental Health and that is an increase, not only in research, but also in research training and, particularly, also in research training for those who are doing work with children and adolescents.

We are particularly pleased that Dr. Judd is the first Director of the National Institute of Mental Health and who also has training in child and adolescent psychiatry and I think will be sensitive to those needs, although I have already found him a very tough and careful negotiator. He is very knowledgeable and we are all, as you are, delighted by his appointment.

Let me urge also support for clinical training without which we cannot continue to revive those people who provide the teaching and the training of those who are going to provide the services. We cannot provide services for those who are currently in need, so clinical training is an important priority.

PREPARED STATEMENT

Of course, support for the services program that is being so enormously successful in multiplying the funds that the Congress has allocated into State support for service programs for children and adolescents has been one of the most successful programs that you have established.

So in all of those areas and for the particular concerns of children and adolescents, I commend increases of the committee.

Thank you.

[The statement follows:]

STATEMENT OF JERRY M. WIENER

The American Academy of Child and Adolescent Psychiatry appreciates this opportunity to testify before the Subcommittee on the President's 1988 budget request for the National Institute of Mental Health.

I am Jerry M. Wiener, M.D., Chairman of the Department of Psychiatry at George Washington University Medical Center, and President of the American Academy of Child and Adolescent Psychiatry. As a representative of the Academy, I am here today to urge members of the Subcommittee to support those programs within the National Institute of Mental Health that contribute to the treatment of and services for children and adolescents. Much of the direction taken by mental illness research and training comes through the Institute, and NIMH programs now influence an ever growing number of state and local decisions about services for the estimated 7 to 12 percent of children and adolescents in this country, who, on a day to day basis, need psychiatric care.

The American Academy of Child and Adolescent Psychiatry

The American Academy of Child and Adolescent Psychiatry is a national, professional association of over 4000 child and adolescent psychiatrists. Its members are physicians who have completed a general psychiatry residency and two years residency training in child and adolescent psychiatry. This medical discipline is concerned with the prevention, diagnosis and treatment of developmental and psychiatric disorders in children, adolescents and their families. These disorders include affective illness, attentional deficit disorders and learning disabilities, schizophrenia, substance abuse, eating disorders, suicide and conduct disturbances.

The Graduate Medical Education National Advisory Committee reviewed the service requirements for treating the psychiatrically ill children and adolescents in this country and recommended that a range of 8,000 to 10,000 child psychiatrists be required for 1990. It now appears that only half of the number recommended can be reached, but the number of children and adolescents in need shows no sign of decreasing.

Recommendations

The Academy appreciates the emphasis the Subcommittee has given to children and adolescents in past report language, especially the recommendations that NIMH clinical training funds be directed to underserved populations including children and adolescents. The clinical training program and the Community Support Program (CSP) have, in the past, been scheduled for elimination through the Administration's recommended zero budgeting of them from FY 1981 through FY 1987; however, Congressional support allowed the programs to continue. In the case of the Community Support Program, children and adolescents received a special benefit through the retention of CSP in the budget. The Child and Adolescent Support Program (CASSP) which grew out of the Community Support Program used modest initial funding to assist in providing services for children and adolescents with psychiatric illnesses in over half the states.

The Administration's FY 1989 NIMH budget requests $10 million for clinical training and $26 million for services demonstrations, amounts which finally begin to recognize the importance of encouraging clinical training and a continuum of services, but not enough to begin to respond to the needs of approximately 12 million youngsters under age 18, with psychiatric illnesses.

For FY 1989, the Academy recommends the following appropriations be made for these NIMH programs:

Clinical Training.........$28 million, including $2 million for NIDA and NIAAA

Research..................$400 million

Research Training.........$26.2 million

Child and Adolescent Service System Program...$15 million

for all Services Demonstrations...............$60.4 million

Clinical Training

The Administration has recommended $10 million in FY 1989 for the NIMH clinical training program, with this funding tied to another three year phase-out plan for the entire program. This phase-out scheme as been in effect before, with the result being uncertainly as to whether grants will be eligible for renewal or simply terminated because of the reduced amount of funding. That uncertainty does not encourage training programs or trainees to respond to the critical need for a constant, intense focus on children and adolescents. The FY 1988 appropriation of $15.8 million meant no new starts could be made in 1987, with the funds being used entirely for 42 continuing grants.

The grants supporting training programs in child and adolescent psychiatry are used to support faculty, not individual trainee stipends, an arrangement that multiplies benefits by contributing to the education of mental health professionals through child and adolescent psychiatry faculty members. Dr. John Schowalter, Chief of Child Psychiatry at the Yale University Child Study Center notes the importance of NIMH clinical training support in this report, "The Yale Child Study Center is an active institution which trains 150 people each year in child psychiatry, psychology, social work, pediatrics, education, and research. We also publish approximately 200 papers per year. Without NIMH support for training and research, our capacities would be severely crippled."

The positive effect of NIMH clinical training support is further explained by Dr. James Harris, Director of Resident Education and Associate Professor of Psychiatry and Pediatrics at Johns Hopkins University School of Medicine. He points out that, "The availability of training support has allowed us to increase the quality of training through the development of comprehensive curricula and both community and university based training sites...It has allowed faculty members to extend their teaching efforts to meet the many needs of children and families...It has also, by its emphasis on priorities of national concern, lead to increased faculty teaching about minorities and encouraged both interest and enthusiasm towards working with the many underserved children and families in this country."

Dr. Harris also notes the difficulties of curtailing training programs because of decreased support. Faculty and students cannot be attracted or curricula expanded when support is withdrawn. Outreach cannot be done and continuing education programs end. If programs cannot meet new residency criteria for certification that will become effective this year, the program may close, and reopening training programs is far more expensive than helping them stay certified and active.

An increase to $26 million for clinical training would allow new starts for grantees, as well as assuring funding for the renewal grants, and providing support for the newer programs within the clinical training division, such as the individual faculty scholar awards. In addition, there will be support for awards for special conferences on issues such as mental illness treatment and services for miniorities, for people with severe mental illnesses, and for multi- and inter- disciplinary conferences of mental health professionals.

In the application for the new individual faculty scholar awards, which were developed to insure the successful preparation, development, and launching

of clinical academic careers, NIMH designates those areas specified by Congress for special emphasis. The application states:

> There is a marked disparity between the need for treatment of major mental disorders and the availability of trained mental health professionals to provide and supervise this treatment. For this reason, the NIMH supports clinical training programs to develop a cadre of academically based teacher/clinicians who will guide the training of professionals in the core mental health disciplines...Four priority areas have been designated: schizophrenic disorders; mood disorders; severe mental disorders of children and adolescents; and the major mental disorders of the aging.

The recognition by Congress and NIMH of the need for special awards of this type must be supported by an adequate appropriation. The American Academy of Child and Adolescent Psychiatry strongly recommends that clinical training be continued beyond 1991, and the appropriation request be increased to $26 million.

Summary

The American Academy of Child and Adolescent Psychiatry expresses it's appreciation for past support for NIMH clinical training, research, research training and services demonstration programs. By continuing each of these programs and allowing increased funding for them, Congress will assure better treatment and services for the millions of children and adolescents with psychiatric disorders.

Senator DOMENICI. Thank you very much, Doctor.

Do you concur with the statement made, heretofore, that because of the increased diagnostic capabilities that are evolving in the profession that we may very well be on the threshold of some new and exciting diagnostic capability and that is one reason that we should proceed with something like the 5-year plan in schizophrenia?

Dr. WIENER. I don't think that there is any question that we have sort of, it seems to me, laid the groundwork at this point with some significant findings, but really have laid the scientific groundwork for what I think is going to be an exciting, if not revolutionary, period in research findings, not only at the basic or molecular, genetic, biological level, but in the understanding of the interaction between those issues and behavior and ways of influencing it at both of those levels. I think we are on the verge. It is going to be the age of the brain in behavior over the next few years.

Senator DOMENICI. Have you also noticed, if this is within your area, have you noticed an increase in interest in young scientists in this field?

Dr. WIENER. No question.

Senator DOMENICI. When you started about 5 or 6 years ago, my recollection was that it was very difficult to attract young, bright scientists because they weren't sure that this was going to be a field with sufficient challenge and sufficient continuity of activity. I am led to believe that that has changed substantially with reference to both the quantity and quality of men and women.

Dr. WIENER. Two things have changed, Senator. The decrease which we saw during the 1970's, in the period of turmoil in the field, the decrease in the number of medical school graduates applying for residency training in psychiatry has reversed and we have seen an increase since about 1982 in the number so that it is now at the level of about 6 to 7 percent of all graduates of medical schools, U.S. medical schools apply for residency training in psychiatry.

But let me tell you what I think is even more important and that I think is also related to the issue of research that we have just spoken about and, that is, that without exception I believe those of us who are in the direction of training programs identify an increase in the quality of the people applying for residency training in psychiatry.

It is an absolutely superb group of young people who are very often at the top of their classes and are very attracted to the field because of the excitement of combining the biological and the psychosocial in the understanding and treatment of illness.

Senator DOMENICI. I was going to ask some additional questions, but I think we are going to run out of time so let me just say I can do that informally with you at a later date. Thank you so much for the time you have given us this morning. Your statement will be made a part of the record.

Dr. WIENER. I appreciate it. Thank you.

STATEMENT OF DAVID H. JOHNSON, PH.D., EXECUTIVE DIRECTOR, FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL, AND COGNITIVE SCIENCES

Senator DOMENICI. Dr. David Johnson, executive director of the Federation of Behavioral, Psychological, and Cognitive Sciences. That is a big name.

Mr. JOHNSON. I don't put it into the testimony so I have more time. We thank the subcommittee for allowing us to present our views on the fiscal year 1989 NIH appropriation.

The summit agreement constrains this year's appropriation process. In that context the President's NIH request is generous. In the context of need, however, that appropriation will exacerbate existing problems at NIH.

Analysts there say a 14-percent increase is needed to maintain current services and provide an additional year of competing grants. Under the current constraints we support the President's request for the NIH but want to outline some problems that will grow more severe under this proposed budget.

1989 will be the second year in a row that the number of new grants will drop at NIH. While this is offset by more noncompeting renewals, the strongest program of research is achieved by a balance of longer-term grants that allow promising ideas to be fully developed and new grants which bring fresh ideas and fresh talent into the research arena.

More fundamental to productive research is maintaining enough funding to carry out the research. A rule of thumb sometimes applied is that if a grant is cut by 15 percent, the research program is essentially dead.

Behavioral and biomedical research costs are rising faster than the rate of inflation. To continue providing a substantial number of awards despite rising costs, NIH has been negotiating grants downward.

In fiscal year 1988 the cut is 7 percent for noncompeting renewals and 11 percent for competing awards. In 1989 cuts will be 9.9 percent and 13.3 percent, respectively. If the size of the cuts continues to rise along with the cost of research, the damage to research is soon going to be severe.

Despite rising costs and downward negotiated budgets, much is going on in health-related behavioral sciences. Let me mention just one promising area.

There is no cure for AIDS, but behavioral intervention models have been implemented in the San Francisco Bay area that have substantially reduced the incidence of new cases of AIDS. By studying the social structure and communications mechanisms of the gay community, and then designing intervention strategies employing these naturally occurring systems, researchers working with community-based organizations have implemented very effective AIDS prevention programs.

PREPARED STATEMENT

The support you have given NIH has produced ways such as this for the citizens of this country to lead longer, healthier, happier lives. We think those are dollars very well spent.

We appreciate the difficulties you have this year and we hope that we can work together to solve those over the years.

Senator DOMENICI. Thank you very much. We appreciate your testimony and your prepared remarks will be made a part of the record.

[The statement follows:]

STATEMENT OF DAVID H. JOHNSON

Mr. Chairman, members of the Subcommittee, my name is David Johnson. I am Executive Director of the Federation of Behavioral, Psychological and Cognitive Sciences. The Federation is an organization of thirteen scientific societies and more than eighty university departments and centers. Our combined membership exceeds 90,000 individuals whose research interests include all aspects of behavioral science and its application to education, health and human development. We thank the Subcommittee for affording us the opportunity to comment on the fiscal year 1989 appropriation for the National Institutes of Health.

The fiscal year 1989 Administration budget request for the National Institutes of Health can perhaps best be described as a mixed blessing. The budget summit agreement between the White House and the Congress sets rigid overall budget boundaries. Despite these boundaries that leave little room for maneuvering, the National Institutes of Health fare well when compared to other programs. The President has requested a rise in funding for the NIH that exceeds the two percent maximum government-wide rise in discretionary spending. Such support for behavioral and biomedical research is welcomed. For the first time in many years, the president has requested an increase for this research, and the scientific societies that make up the Federation support this request for increased funding.

I call this blessing mixed, however, because despite the rise in requested funding, it is expected that cuts will need to be made in some of the activities of the Institutes in order to operate within the requested amount. NIH analysts calculate that a budget that would allow NIH to maintain the current level of services and to make one more year of awards would require a budget increase of fourteen percent.

While we support the President's request for NIH, we must point out that this level of funding will have some adverse effects on research and training. If the limitations that exist this year in the budget process were not as stringent as they are, we would recommend to this Subcommittee that, at the very least, it seek to fund the Institutes at a level that would allow maintenance of current services. Nothing is as basic to the quality of human existence as health. And nothing is as essential to improving the quality of health and health care as a vigorous program of research.

The budget for AIDS research and prevention activities is being considered separately from the NIH appropriation because those activities are carried out across a number of agencies. Since a portion of the AIDS appropriation would go to NIH, we think it appropriate to state at this point that we are endorsing the recommendation of the Coalition for AIDS Prevention and Education with respect to this activity. That recommendation is for a funding level of $1.9 billion for all AIDS research and prevention activities. Fifty-nine million dollars of the increase over the President's request for this activity would go to NIH. We have decided to support this recommendation because we are convinced from research evidence available now that a great deal can be done immediately through behavioral change programs to slow or even stop the spread of AIDS. Moreover, we believe that there is an immediate and pressing need to develop and implement humane treatment and patient care models.

Let me return to the non-AIDS portion of the NIH budget. Even though it is not realistic to believe that solutions can be found during the coming fiscal year to the problems that are developing at NIH in part because of funding levels, it should be useful to the Subcommittee to know what some of the difficulties are because they will soon need to be addressed.

Of concern to scientists is the amount of research that can be carried out under current funding conditions. The problem manifests itself in at least two ways. First, it appears likely that 1989 will mark the second year in a row that the number of new and competing awards will decline. It is expected that about 254 fewer awards of this kind will be given in FY 1989 than were given in 1988. Compensating for that decline is a rise in non-competing renewals. But the mix between competing awards and non-competing renewals is itself a matter that is potentially of concern. A subtle effect of this shift in funding is that it brings pressure on researchers to make certain that their proposal will be universally acceptable. Taking a chance on a truly innovative idea is discouraged because objections from peer reviewers will drive ratings down. In an atmosphere where even highly rated proposals are not funded, no researcher can afford to take a chance on creativity. The advantage of a sufficient number of new awards is that they provide an avenue for both fresh talent and fresh ideas to enter the research arena. The advantage of non-competing renewals is that scientists have grants of sufficient duration to establish very strong and productive research programs. They are able to pursue ideas to their conclusions. If the national program of research in the health sciences is to be most productive, then it must have a balance between research that introduces new ideas and research that develops ideas to their conclusions.

The second way the funding problem affects the amount of research that can be done is through what is called "downward negotiation" of grant awards. The term refers to the practice of routinely reducing the size of the new or existing grant by a standard percentage. In 1988, the downward negotiation for noncompeting renewals was about 7% and that for competing awards was about 11%. It is expected that the 1989 downward negotiations will be about 9.9% for noncompeting renewals and about 13.3% for competing awards. The concern of scientists is that the level of cuts might reach such a point that they make it impossible to carry out the intended program of research. A cut of 15% is often cited as a level beyond which the intended research can no longer be carried out. The expected cut for competing awards in 1989 comes within less than 2% of breaching that make or break point.

An analagous problem is to be found in the support of NIH research centers. Many of the centers have seen several years of steady-state funding. At the same time, the cost of doing health-related research has been growing at a rate that is faster than the national rate of inflation. What this means is that steady-state funding has actually resulted in an erosion of the funding base. The situation had reached a point in some Institutes such as the

National Institute of Child Health and Human Development that consideration had been given to the possibility of closing some centers in order to use their funds to keep the remaining centers functioning. The FY 1989 request, if fully funded, should relieve some of the pressure on centers.

The effects of restricted funding that I have outlined to this point have been effects directly on research. In order to continue to fund a substantial number of research projects and centers even in a time of fiscal restraint, some activites that relate to the infrastructure of research have been neglected. While the budget for AIDS research has had a modest amount of money for updating facilities so that they will be safe places in which to conduct AIDS research, there is little facilities money available for other kinds of research. This lack of money to improve facilities has extended even to NIH's own campus where in some departments operating funds have been restricted in order to maintain support for other activities. Such deferments can be absorbed for a time, but eventually the deterioration of facilities will affect the quality of research carried out within the facilities.

Despite the pressures under which health-related research has been conducted in the recent past, a great deal of exciting and important work has been and is being carried out. This Subcommittee has been a strong and constant champion of research conducted under the auspices of NIH. I would like to tell the Members about a few of the areas of behavioral research related to health where important advances are being made.

AIDS is a matter of deep concern across the country. Even the most optimistic of researchers does not expect a cure to be found in less than a decade. In the mean time, behavioral changes offer the greatest hope of stopping the disease. San Francisco has been one of the cities hardest hit by AIDS. Recently the incidence of new cases of AIDS has declined markedly in the Bay Area. One major reason for that decline is that behavioral scientists have been working closely with the gay community and with city officials to identify and make use of the communications devices that are a part of the social structure of the community in the Bay Area. After careful study of the ways that information is gathered and disseminated in the Bay Area, the researchers and service delivery personnel have been able to use the social structure to spread information rapidly and effectively and to make service delivery easily accessible and acceptable. The behavioral intervention models developed in the Bay Area should also be able to control AIDS in other communities with organized, identifiable community social structures. It is in part the success of the San Francisco research that has led us to support the level of increased funding for AIDS prevention and treatment research that is being proposed by the Coalition for AIDS Prevention and Education.

In a quite different realm of research, behavioral scientists have been learning about the health implications of natural cycles. It is becoming clear that human and animal behavior is regulated by cycles to a much greater degree than had been previously imagined. The female menstrual cycle and the cycle of waking and sleeping are so much a part of existence that we take them for granted. There are other much less salient cycles now under investigation.

The sensitivity of our sight and hearing, for example, varies in a diurnal cycle or rhythm. Of special interest to researchers are the health effects of interruptions in these natural cycles. Illnesses that occur commonly after long-distance air travel may be caused in part by cyclical interruptions. There is also active investigation of the role of cycles in sleep disturbances, and in some types of psychopathology.

Much exciting research is taking place at the intersection of biology and psychology. The discovery several years ago of reward mechanisms in the brain was the result of behavioral scientists making new use of neuroscience techniques. Since that discovery, the effects of abused drugs on the natural reward systems of the brain have become much better understood. There is great promise in this research of finding chemicals that can act as antidotes to drug addiction by blocking the influence of illicit drugs on these neural reward systems.

Another area of important work that combines biomedical and behavioral research has to do with the role of behavioral and social variables on bodily chemistry and on the frequency and severity of illnessess. The work is likely to have many applications. Some research, for example, is indicating that psychological stress can affect the immune system making people more vulnerable to infectious diseases. Interestingly, some of these effects may be different for men than for women. The life span of men, for example, can be shortened by loss of a spouse. There does not seem to be such a-bereavement effect for women. Research over the past few years in nursing homes has shown that the life span of the elderly can be lengthened by allowing nursing home residents greater control over their daily activities. Nursing homes where residents are treated as invalids, such that all control over their daily routine is exercised by persons other than themselves may be unnecessarily shortening the lives of residents. In related research, the question of the effects of social support systems for the ill and elderly is being explored. Once again, it appears that there may be important sex differences associated with support system effects. Older men living alone, for example, are less likely than older men living with someone else to receive proper nutrition. The rate and severity of illness is also higher for older men living alone. Such effects are much less prominent among older women living alone. That is, they are more likely than their male counterparts to receive proper nutrition, to be healthy, and to live longer.

These and other discoveries of behavioral scientists working on health questions suggest pathways for further exploration and for application to health improvement. Can the reductions in the incidence of AIDS achieved in San Francisco be replicated in other communities? Can the lives of the elderly be reliably prolonged and their health improved through alteration of their social settings and through giving residents greater control over their lives in institutional settings? Can we use knowledge about natural bodily cycles in controlling mental disturbances and in reducing susceptability to infectious diseases? Can antidotes be developed for drug addiction? The support you give to the National Institutes of Health is what will make it possible to answer these questions. In the end, the support you give to NIH will make it possible for the citizens of this country to lead longer, healthier, happier lives. We think those are tax dollars very well spent.

Senator DOMENICI. Senator Weicker, we have two witnesses that you were interested in. We will call them now, if that is all right with you.

STATEMENT OF ROGER E. MEYER, M.D., UNIVERSITY OF CONNECTICUT SCHOOL OF MEDICINE, THE AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY

Senator DOMENICI. Roger Meyer, Dr. Meyer, University of Connecticut School of Medicine, the American College of Neuropsychopharmacology.

Dr. MEYER. I am speaking today on behalf of the American College of Neuropsychopharmacology which is a nonprofit educational and scientific society which represents 430 research scientists who are elected to membership on the basis of their recognized scientific contributions. ACNP constitutes the most active group of scientists in the United States involved in the research areas covered by the three component institutes of the Alcohol, Drug Abuse, and Mental Health Administration.

I feel like I am sitting in a cab here with the meter running. I would like to make several points apart from my prepared testimony. I think that a number of people have commented upon the extraordinary developments of a concerned coalition of scientists and advocacy groups and consumers who are concerned about the ADAMHA budget, the development that really has only taken place within this decade. We are delighted at ACNP with the quality of leadership that has been attracted to NIMH, to NIAAA and to NIDA, to reflect the importance of the scientific missions of those three institutes.

We are also extremely delighted with the scientific developments in areas of brain and behavior which have taken place literally over the last 5 to 10 years but especially in the last 5 years when we have learned more than 90 percent of what we know about the brain, and that is really a credit to this subcommittee and its support for this research budget.

These developments would not have taken place if this subcommittee had not repeatedly gone well beyond the recommendations of the administration.

I call to your attention a professional judgment budget that others have drawn to your attention, $400 million for NIMH, $102 million for NIAAA, and $150 million for NIDA. These budgets are based on a reasonable scientific infrastructure which you have helped to create and it is poised for important scientific progress.

The NIMH professional judgment budget calls for a schizophrenia initiative which is not only based upon the extraordinary need and cost of this disorder, but also because of the opportunities to study brain mechanisms, to study genetics, and to study promising new pharmacotherapies. We are also hoping to see an expansion of research to further elucidate brain mechanisms, to really dedicate ourselves to a decade of the brain.

Through NIAAA the genetics of alcoholism has been an extraordinary explosion of information identifying the important subtypes that are comparable to the identification of subtypes in areas of diabetes. For NIDA there is a growing concern about identifying populations at risk and for developing new treatments for cocaine abusers and other drug abusers.

We all know, as you pointed out, Senator Domenici, at the beginning the extraordinary budget constraints that we are operating under. We also hear about a drug abuse initiative that is being moved in the House and may be moving as well in the Senate.

I would only urge that you do what was done in 1986, that if there is an omnibus drug bill, that it attend to the research budgets at NIDA and at NIAAA and that it particularly attend to alcohol research as well as drug abuse research, an issue which you addressed in the Congress in 1986 and was largely forgotten in the war on drugs of the 1970's.

I think it is critical that you do this because we really don't have good treatments for cocaine even though we have a large demand side there.

PREPARED STATEMENT

Finally, I want to express again my appreciation to this subcommittee for its continuing, strong, and unflagging support for ADAMHA research despite fiscal constraints. It is my hope that you will continue to do so on behalf of the families of the mentally ill and addicted and that we can continue to see the kinds of support that we have had before.

Thank you very much.

[The statement follows:]

STATEMENT OF ROGER E. MEYER

Mr. Chairman and Members of the Subcommittee, my name is Dr. Roger E. Meyer. I am Professor and Chairman of the Department of Psychiatry and Scientific Director of the Alcoholism Research Center at the University of Connecticut School of Medicine.

I am appearing before you today on behalf of the American College of Neuropsychopharmacology, a nonprofit educational and scientific association. ACNP is an interdisciplinary organization concerned with research about biological function in the central nervous system and its relationship to the causes and treatment of mental and addictive disorders. Its membership consists of more than 430 research scientists elected to membership on the basis of recognized scientific contributions. The ACNP membership constitutes the most active and distinguished group of scientists in the United States involved in the research areas covered by the three component Institutes of the Alcohol, Drug Abuse and Mental Health Administration.

I appreciate the opportunity to speak to you today to share ACNP's views on the importance of basic biomedical and behavioral research as an element of ADAMHA's overall program to address the problems of alcoholism, drug abuse, and mental illness. Important research advances in the past few years underscore the vital need that exists to increase funding levels for basic biomedical and behavioral research so that we may expand our knowledge in these areas and lay a solid foundation for medical and scientific breakthroughs in treating and preventing these disorders. More than 90% of what we presently know about the brain has been generated during this decade.

At the outset, I would like to express my profound appreciation to this Subcommittee for its strong and unflagging support of biomedical research efforts. In recent years, your leadership has made possible a steady annual growth in the ADAMHA research budget, despite fiscal restraints. Your financial support of basic and clinical research projects continues to generate important findings that will lead to the prevention and improved treatment of addictive and mental disorders.

This Subcommittee has heard earlier testimony that the annual cost of health problems associated with ADAMHA programs has been calculated at $249 billion. This figure includes direct and indirect costs related to mental illness and addictive disorders, including expenses connected with health care, reduced productivity, accidents and violence. Although we are pleased that the President's ADAMHA research budget proposal for FY 89 is at an all-time high -- $458.7 million, up $22.4 million from FY 88 -- we would note that this represents only a fraction of the total costs associated with these disease states. The myriad and provocative research opportunities which currently exist and are ripe for investigation are proof of the wisdom of supporting an expanded research program.

In recent years, there have been a number of exciting discoveries in basic neuroscience research that hold great promise for the future. For example, recent research on the factors regulating the activity of the brain is contributing to significant advances in our understanding of schizophrenia, mental illness, alcoholism, and heroin and cocaine dependence.

In one investigation, researchers have discovered, through the use of noninvasive methods to study blood flow and glucose utilization in very discrete regions of the brain, that untreated young male schizophrenics have significant underactivity in the left subcortical area. This is the first suggestion we have seen that there is a specific pathologic process detectable objectively in the living brain uncontaminated by drug effect.

Other studies have led to the discovery of a chemical intermediate which may represent the basis for the therapeutic actions of lithium. This intermediate allows certain neurons to respond to those neurotransmitters which have already been intensively scrutinized in manic depressive disease.

Further progress has been made in our understanding of how the brain works through research demonstrating that a new brain transmitter may normally use for its signal recognition site those points on the surface of certain neurons through which tranquilizing drugs treat anxiety. This new transmitter molecule may help reveal the sites where alcohol produces intoxication and elicits in some individuals a continuing reliance on alcohol for the reduction of anxiety.

In the area of drug abuse, significant gains have been made in identifying the sites in the brain at which heroin and cocaine produce their reinforcing euphoric effects. Clinical research has identified non-addicting drugs for the treatment of heroin withdrawal, and the withdrawal state associated with cocaine. NIDA is supporting studies designed to test new treatments for cocaine and heroin addicts.

Advances in the genetics area include reports by separate groups of researchers that at least two potential gene markers may be linked to affective disorders in different populations. If these studies can be replicated and the differences explained, these linkage markers may be used to begin to define the nature of gene products that may make certain individuals more susceptible to a disease. Genetic approaches to alcoholism and schizophrenia sub-types are under active consideration since there already exists strong epidemiological data indicating heritable transmission of susceptibility.

These are only a few examples of recent research activity in the area of alcoholism, drug abuse, and mental illness. These and other research discoveries provide the data and clues that are necessary to generate the solutions to problems of human medical and social diseases.

Turning now to the President's FY budget, I'd like to draw your attention to two items in particular. The President has requested an increase in funding levels for two NIMH initiatives -- the schizophrenia initiative, to $40.2 million, and the basic neuroscience research initiative, to $97.1 million. For schizophrenia, the initiative includes efforts to document the extent of this health problem and to develop a national research effort to identify its causes and develop more effective treatments. For neuroscience, NIMH has identified promising areas of research effort within this as-yet relatively undeveloped scientific field. These initiatives represent important national goals and are worthy of the strong continued support of this Subcommittee. I urge your attention to the recommendations of the coalition supporting a professional judgement budget for NIMH research that would fund the National Plan for Schizophrenia Research and the Decade of the Brain.

I would urge your attention to the need for research on risk factors associated with drug and alcohol abuse, the genetics of alcoholism and experimental treatments of addictive disorders. Language in the reauthorizing legislation for NIAAA (S1943) specifically authorizes funding a major initiative on the genetics of alcoholism. The professional judgement budgets for NIAAA ($102 million) and NIDA ($150 million) would enable these Institutes to fund these programs. In the context of any new appropriations for Drug Abuse Programs, I urge you to not forget alcoholism -- and that you include these initiatives for research (as described above). In the aftermath of the recent report on smoking by the Surgeon General, funding for the Drug Abuse initiative might come from increased taxes on cigarettes - the gateway drug to other drugs of abuse.

Mr. Chairman and Members of the Subcommittee, ACNP firmly believes that the key to unlocking the secrets of alcoholism, drug abuse and mental illness and to developing effective methods for their treatment and prevention will ultimately be found in the discoveries arising out of biomedical and behavioral research. As in the past, we in the scientific community join with patients and families to urge your continued support for these research programs.

Senator DOMENICI. Thank you.

Senator Weicker, do you have any questions?

Senator WEICKER. I note that Dr. Meyer has politely laid his finger on a problem here, which is that funds for drug addiction programs have been cut in the last big war on drugs in the last election year in 1986. Here we are and we have another war on drugs and we were not even willing to live up to the commitments we made in the first war on drugs.

I don't see how we can have an overall drug strategy unless drug addiction programs are certainly involved in that strategy. Am I not correct, in the State of Connecticut—and I don't think we are atypical—am I not correct then, sir, that we have got people waiting?

Dr. MEYER. We have got a 6-month waiting list.

Senator WEICKER. A 6-month waiting period for the drug addiction programs in the State of Connecticut.

I thank you for coming today.

Senator DOMENICI. Could I ask you a question about how your profession relates to the rest of those involved in the field of treating mental illnesses?

Dr. MEYER. I am also chairman of the Department of Psychiatry at the University of Connecticut and head of our Alcohol Research Center, and a member of the American College of Neuropsychopharmacology.

Senator DOMENICI. How many of your specific expertise are there in the Nation? There is a very small number as compared to psychiatrists, is that not correct?

Dr. MEYER. In terms of the alcohol and drug abuse area, particularly alcohol and drug research, it is a very small percentage of people.

Senator DOMENICI. I mean neuropsychopharmacology.

Dr. MEYER. Oh, we have 430 members from a variety of disciplines, basic scientists, and clinical investigators. It is an elected membership and I think a more accurate reflection of the larger number of scientists involved in this field, the society for neuroscience, which involves several thousand scientists, but in terms of psychiatrists involved in this area, the psychiatrists who are most actively involved are a part of the American College of Neuropsychopharmacology.

Senator DOMENICI. As a general proposition, do not many of your profession consult with psychiatrists and others on medicine and medication? Is that not one of the things that you do?

Dr. MEYER. Yes; we have an active program of education for psychiatrists in psychopharmacology. We have a model curriculum that we have developed for our medical schools, for medical students, and for psychiatric residents.

We have fellowship programs to invite young psychiatrists to our meetings and provide an active continuing education program.

Senator DOMENICI. Without wanting to insert myself in the ongoing debate among psychiatrists, could I ask for your opinion? Are psychiatrists in the United States, in your opinion, beginning to use the kind of professional expertise that you have with reference to drug intervention and the use of drugs in the treatment of the mentally ill? Are they beginning to use your kind of expertise more these days than they were, say, 5 years ago?

Dr. MEYER. I certainly believe that we are seeing a tremendous increase in sophistication about the use of medications by psychiatrists. I think that this was a problem in the 1970's because many people had been trained a number of years earlier. I think the technology is being more rapidly incorporated into practice in ways that it had not been in the 1970's.

Senator DOMENICI. Would it be your opinion that the curriculum in U.S. medical schools that specialize in psychiatry, focuses more attention in the area that you are speaking of than they were 5 or 10 years ago?

Dr. MEYER. I don't know of a school that is not doing that. Yes; I think that the Residency Review Committee in Psychiatry and Neurology really sets, I think, very, very excellent standards on the education of psychiatrists in areas of biological psychiatry and psychopharmacology.

Senator DOMENICI. So there shouldn't be an excuse any longer with reference to such a simple treatment as lithium, is that correct?

Dr. MEYER. There shouldn't be an excuse. I think unfortunately one will always find the exception and the exception will always get into the newspapers. That is a burden that we in our field live with and one that we have to account for because we have to go for 100 percent perfection. I think that is our responsibility.

Senator DOMENICI. Thank you very much.

Dr. MEYER. Thank you.

STATEMENT OF ELEANOR S. KOHN, VICE PRESIDENT FOR PUBLIC POLICY, NATIONAL MENTAL HEALTH ASSOCIATION

Senator WEICKER. Eleanor Kohn, vice president of the public policy, National Mental Health Association. Nice to have you here. Ellie and I are constant companions on a flight from Washington to Westchester.

Ms. KOHN. Unfortunately, the planes are too noisy for me to do much lobbying. I represent the National Mental Health Association, which, as you all know, is a volunteer organization representing some 1 million members around the country.

When I testified last before this committee, Senator Weicker, you said to me, Mrs. Kohn, this committee doesn't need convincing, it is the public that is dead in the water. We agree with you. This committee doesn't need convincing.

We believe the committee has a deep understanding of the kind of agony that people with mental illness face, the kind of agony that their families face, but we don't think that understanding is shared by all of your colleagues here on the Hill and we don't think that understanding is shared by the public.

And we are here today to ask you to take on an additional job. We are asking you, this committee, to become the Nation's lead lobbyists for people with mental illnesses. Homeless people with mental illness can't do their own lobbying. They don't have papers and pencils in the crates that they are living in on the streets. People locked in the back wards of State hospitals can't do their own lobbying. They need somebody someplace to take on the job.

This committee has the knowledge, they have the power, they have the leadership role. In the whole country there is no group of advocates in a better position to do what must be done. The rest of Congress, the administration, the public needs to know of your conviction, your conviction that an illness that affects 15 to 20 percent of this population can't any longer be relegated to the bottom of the health funding heap, and that is what has happened, what has been happening with mental illness for years.

They need to know of your conviction that there is really astounding research promise in the field. It is a promise that warrants a major investment that is receptive not only of that promise but also of the staggering cost to the Nation.

We know, Senator Weicker, that this isn't going to be an easy fight given this year's fiscal restraints, but we, the volunteer advocacy groups, all of the people you have heard from this morning, the scientists, the people with mental illnesses and their families, the professionals, we can help, but in the long run it is going to be this committee and this committee primarily which will make the real difference.

You have already received a copy of our detailed written testimony. The Mental Health Association wants to call your attention to two specific items, one our request for $400 million for NIMH research.

The second request is something you haven't heard about this morning. We are asking for a $35 million appropriation to fund the block grant for services to homeless individuals with mental illness. I know what is going on in Connecticut, and I think you probably do, too. The lack of affordable housing is having a devastating effect, especially on people with psychiatric disabilities.

PREPARED STATEMENT

Our State, Senator, is using Federal money to set up programs to deal with those people. The Mental Health Association around the country is urging the States to expand those programs. We have put together a small directory of actions that our affiliates can take, and I am going to leave some copies with you, but we have got to have adequate funding to help expand those services.

Once again, we, mental health associations, NAMI, professional groups, we can help, but it is you who must lead the way.

Thank you.

[The statement follows:]

STATEMENT OF ELEANOR S. KOHN

Mr. Chairman, my name is Eleanor Kohn, and I am Vice President of Public Policy for the National Mental Health Association, a private, voluntary organization providing leadership to confront the entire range of mental health issues at local, state and national levels.

My testimony today is built on hope. That hope has been spawned by two extraordinary documents recently released by the National Institute of Mental Health. The first is the Schizophrenia Plan, an initiative which, as you know, began some two years ago at the Institute in an effort to address, in an integrated and comprehensive manner, the problems and opportunities which are now in the forefront of our nation's struggle to deal with this devastating illness. The Plan also responds to an oft-repeated concern of Congress that concerted attention be focused on the major mental illnesses. Although that concern is certainly one that has been shared by advocates like the NMHA as well as the scientific world, it is only fairly recently that the field has developed the appropriate broad base of knowledge and the complex technology to assure that investment of scarce resources will produce a long sought pay off.

The second document, "The Decade of the Brain," is geared to the remarkable advances being made in the neurosciences. This impressive report emphasizes the timeliness of an expanded effort in neuroscientific research on mental illness: "We are poised for neuroscience breakthroughs in the 1990s that will generate clinical success during the twenty-first century."

Mental Health Research

It is significant to note that the "Decade of the Brain" report and the Schizophrenia Plan devote page after page to a description of the several types of brain imaging techniques which provide maps, pictures and measurements of the living, thinking and functioning brain in minute and exquisite detail. This is all the more remarkable because scarcely a decade ago, this capability was virtually unknown. It is an absolutely vital but expensive tool on which progress in the field of mental illness is dependent.

I am certain that this Committee and its staff have reviewed both the Schizophrenia Plan and the "Decade of the Brain" in detail as they have studied the appropriation needs of NIMH. The National Mental Health Association has done the same and finds in those papers ample justification for our request for a research appropriation of $400 million for FY 1989.

When advocates appeared before Congress in the late 70's requesting significant increases in NIMH's dollars, we were told that the research was not ready for a major infusion of dollars. That can no longer be said--the mental health field is explosive with promise. The opportunity for developing new knowledge is virtually unlimited and it is not unrealistic to expect that the next ten years will propel us further down the path to conquering mental illnesses than all the years preceding. To allow inadequate resources to slow that progress is unthinkable. A few years ago, this subcommittee, in its Appropriations report, described the NIMH research program as "...one of vital potential for addressing illnesses that afflict and handicap millions of Americans". We could not agree more with your choice of terms "vital potential" but that potential will only be reached if support is available to further develop it. The decisions being made by this Committee are as important to those millions of Americans suffering from mental illness as is the work of research scientists.

We know you will find the report on the advances in the neuroscience of mental illnesses an effective document for supporting a recommendation for a major increase in NIMH research funding. We are confident it will also be extremely useful in persuading your colleagues of the merit, necessity and timeliness of investing realistic resources in the battle against the mental illnesses.

It is difficult to understand a national policy which supports the expenditure of $2000 per person on health care and only $25 per person on medical research to reduce this cost. The discrepancy in the mental health field is even more glaring. For every person with cancer, $134 is invested but only $34 for every person with mental illness.

While only 1/5 of those identified as having a mental disorder are in treatment, patients with mental disorders still account for the majority of hospital beds in the U.S. We know this Committee must have concerns, first about those who need but do not get treatment and secondly about the soaring costs borne by governmental systems besides health care--the legal, penal, welfare and social service systems. Although you have been hearing the statistic ever since the 1984 Institute of Medicine report, it bears repeating over and over again----if research on schizophrenic illnesses yielded an intervention that reduced costs even by 10% annually, in 10 years, it would save a total of $180 billion. It is true that prevention and/or cure of mental illnesses may not be immediately achievable but it is now entirely possible, even probable, that dramatic improvements in treatment for some forms of schizophrenia may very soon make these $180 billion projected reductions a reality.

In the area of the affective disorders, we are already able to cite data which supports the cost effectiveness of new research findings. Until recently, it could be said that 70% of patients diagnosed with affective disorders, who receive appropriate treatment, were able to resume normal functioning. That 70% figure is now 85%, as a direct result of research which has led to the use of Tegretol and other anti-convulsants in effectively treating rapid cycling manic depression. This group has been identified as the most seriously ill of manic depressives and the heaviest users of costly inpatient services.

More and more data is accumulating, underscoring the interface between the biological and behavioral sciences. This has widespread implications for furthering understanding of a host of subjects as widely disparate as mental illness in children and AIDS. As one example, there is a whole range of neurobiological studies and revealing evidence of the negative effects of stress on still developing brains which provides support for the hypothesis that intermittent stress is far more damaging than chronic stress. To cite a specific, children who have been sexually abused show discernible evidence of brain changes. For many children with those clearly identified physical changes, adolescence brings the development of extremely serious and disabling mental disorders. Obviously, enhanced understanding of the effect of environmental stress on brain function and the possible development of interventions to minimize its damaging effect will have major impact on service utilization in the next decade.

It is also entirely realistic to expect that increased understanding of the brain and its functioning will lead to help for children and adults suffering from a variety of learning disabilities, another costly and debilitating brain dysfunction.

For all these reasons, we are disturbed by the $270 million research funding recommendation of the Administration. This figure in no way reflects either the widespread suffering and costs engendered by mental disorders or the extraordinary scientific opportunities now emerging which, we firmly believe, can serve to decrease both the tremendous fiscal and emotional toll of these illnesses.

In the early 70's, Congress recognized the readiness of the biomedical field to significantly advance knowledge about cardiovascular and hypertensive diseases. Funding for those problems became a major priority and our nation is now reaping the benefit of that investment in more effective treatment, fewer hospital days, significantly lower death rates, reduced incidence and increased public awareness. NIMH supported research has reached an equal state of readiness and we are asking that it be accorded the same high priority. The $400 million research allocation which we are recommending is an investment, not an expenditure.

AIDS Research

We are asking for $66.8 million to enable NIMH to pursue promising leads in AIDS research. The need to explore every avenue in an effort to control and eventually wipe out this disease is certainly one of the priorities of this Committee as it responds to public concerns.

One of those leads being pursued by NIMH will examine the brain's effect on the alteration of the immune system--psychoimmunology. This approach is not only adding to our understanding of AIDS but also adding knowledge about a host of other illnesses. The demarcation between the brain and body are fast fading as these highly productive research efforts move forward. AIDS research on viruses which attack nerve cells has led to an exploration of possible viral infection in the etiology of some forms of schizophrenia. In short, research on the neurovirology of AIDS may well produce both answers to the AIDS problem, and an avalanche of basic knowledge about the brain, its function and dysfunction.

In addition, since the bottom line of AIDS prevention appears to be related to behavioral change, it is imperative that funding support be given

NIMH for work going on in the social and behavioral sciences as well as the neurosciences. Treatment of AIDS is also the focus of NIMH research programs. Very preliminary and limited clinical trials are being conducted using neuropeptides which have produced encouraging results in blocking virus entry into the brain cells. Other trials seem promising in the early detection of AIDS infected individuals. This would certainly carry both scientific and social benefits.

NIMH must also carry major responsibility for developing educational and public information activities which call for another research base.

NIMH's ability to slow down the fast rising mortality and morbidity rates of AIDS is directly related to the resources it is given to do the job.

PREVENTION

In the House and Senate versions of the Alcohol, Drug Abuse, and Mental Health Block Grant reauthorizations bill is a new Prevention demonstration program that would give the Secretary of Health and Human Services, acting through the Director of NIMH, the authority to make grants to states and localities for prevention demonstration projects for the provision of prevention services for individivuals who are at risk of developing mental illness. These projects would put into practice what research has already demonstrated is effective. We are requesting that the Committee fund this new program at $5 million which is the authorized amount in the Senate version of the bill (S 1943), already approved by the Committee on Labor and Human Resources.

HOMELESSNES

There is no issue which pricks the public's conscience more than that of the homeless of this nation. The public has every right to expect the Federal government to take some responsibility and leadership in finding appropriate ways of ameliorating the suffering of individuals and families resulting from the lack of decent and affordable housing. People with long-term mental illness, estimated as 1/3 of the total (according to the National Institute of Mental Health), undoubtedly constitute the largest, single identifiable group within the ranks of the homeless. The conversion or destruction of some 1 million single room occupancy hotels between 1970-80 created huge gaps in available housing for this population. An additional 60-80,000 people with serious mental illness are at high risk of homelessness in the near future because they are now living in unsafe and substandard boarding homes.

Homelessness is not an issue which can be addressed by quick fixes or single answer measures. This at-risk population needs not only a broad range of housing options, but also a broad range of support services. What they don't need is a broad scale, scatter-shot return to institutional care which some are calling for. That is an inappropriate, unwarranted and dead-end approach for people who could live in the community if a reasonable support system were in place.

We are seeking, from this committee, the proactive Congressional leadership necessary to confront the growing problem. Funding is needed to assure that services to homeless individuals with mental illnesses are expanded. We are asking the House Committee on Energy and Commerce to reauthorize the Block Grant for services to homeless individuals with mental illnesses at a $100 million level and we are requesting an appropriation from this committee for that same amount.

The Federal/state partnership which Congress is looking to encourage is indeed strengthening. As of March 1988, forty-three states have applied for block grant funds which require a $1 match for every $3 of Federal grant. Research shows that homeless mentally ill people have a high level of interest in receiving help, particularly for "residential, case management and day programs," but they are reluctant to use traditional mental health services characterized by waiting lines and scheduled appointments in an office. This grant program responds to the unique needs of those individuals by providing outreach, community mental health services, referral for medical and primary health services and for substance abuse services, training, case management, and supportive and supervisory services in residential settings.

Mental Health Services--Alcohol Drug Abuse and Mental Health Block Grant & Services Demonstrations

In addition to the Homeless Mental Health Services Block Grant, the Alcohol, Drug Abuse and Mental Health Block Grant can also be used to remedy the appalling conditions facing homeless persons with a mental illness as well as providing programs for a host of other high risk populations.

Our testimony on the responsibility of the Federal government in the broad

area of service and service systems has been taken almost word for word from the Report by the House Committee on Government Operations with which we are certain you are familiar. We could not have put together a more compelling report to underscore our request for $601.5 million to fund the ADM Block Grant. The report is aptly titled "From Back Wards to Back Streets: The Failure of the Federal Government in Providing Services for the Mentally Ill". We quote some of the headings. MENTAL ILLNESS COST $73 BILLION EACH YEAR, BUT THE SERVICES AVAILABLE ARE OFTEN FRAGMENTED, INAPPROPRIATE, AND INADEQUATE. THERE IS A DESPERATE LACK OF COMMUNITY SERVICES FOR THE MOST SEVERELY MENTALLY ILL. THE COMMUNITY SUPPORT PROGRAM IS EFFECTIVE, BUT SEVERELY UNDERFUNDED. FEDERALLY SUPPORTED RESEARCH AND EVALUATION IS NEEDED TO ASSIST STATES IN DETERMINING WHAT WORKS, ESPECIALLY WITH THE HOMELESS MENTALLY ILL, THE VIOLENT MENTALLY ILL, AND OTHER SERIOUSLY MENTALLY ILL INDIVIDUALS.
And then we go on to the report's recommendations: NIMH FUNDING AND STAFFING LEVELS MUST BE RESTORED TO PRE-1981 LEVELS, TO ENABLE THE FEDERAL GOVERNMENT TO EFFECTIVELY SUPPORT STATES AND COMMUNITIES IN PROVIDING SERVICES TO THE MENTALLY ILL. FUNDING AND STAFFING FOR RESEARCH AND EVALUATION OF MENTAL HEALTH SERVICES AND SERVICE SYSTEMS, AND LEGAL ISSUES THAT INFLUENCE SERVICES, SHOULD BE INCREASED.

The House report also states: "If the Federal Government is providing so little support to States for direct services, and so little guidance in how the funds should be spent, it becomes even more crucial that the Government provide adequate leadership by funding demonstration projects....There is a tremendous need for Federal funding of major model programs and demonstration projects, aimed at coordinating community services for the mentally ill.

We are indebted to the Government Operations Committee for providing us with these cogent statements to substantiate our request for increasing funding for the Services programs of the NIMH.

We recognize that this committee is often put in the unenviable position of having to rob Peter to pay Paul. We also recognize that the Federal budget process limits the Peters available to you but a recent Gallup poll indicates that 76% of the country's voters oppose the reduction of government spending on programs such as health and education. Moreover, after adjusting for inflation, spending on civilian research and development has already fallen 30%

since 1980. These facts certainly point to the inadvisability of across-the-board cuts.

One has only to read the daily newspapers to come up with dollars to respond to voters' priorities. By using the Freedom of Information Act, a reporter discovered a list of approved expenditures for humanitarian aid to the Contras. Included was $5700 for deodorants, $1000 for volleyball equipment, $2200 for living room furniture, three color TVs at $1000 each and $6750 for 620 boxes of candy! Those dollars might better be applied to our Homeless Block Grant for the funding of humanitarian aid at home. The purchase of 131 instead of 132 Stealth bombers, which the Pentagon is planning on, would free up enough money to pay for every one of our recommended allocations except for Research and the ADM Block Grant.

We look to this committee for support in providing the resources necessary to enable the Federal Government to carry out its responsibility not just to the victims of mental illness and their families but to each and every one of us. Until the causes are uncovered and the cures devised, the spectre of mental illness, which annually strikes 15-20% of the population, will haunt one out of every five in your family and among your friends and colleagues. The hope that permeates the field can become reality given the resources necessary to make it happen.

Senator WEICKER. Eleanor, thank you very much for your testimony. I also want to point out that the committee probably would reject the administration's request to cut and phase out the protection and advocacy program for the mentally ill, which is another matter that was dropped into our lap.

As you know, we just recently put into law protection and advocacy for the mentally ill and the response of the administration is to cut the program by $2.5 million with a phaseout in the future. And I must confess, I don't understand who thinks of these matters, but, in any event, I can you assure the committee will reject the administration's request and will certainly give serious consideration to your concerns.

Ms. KOHN. I must tell you that I am very proud to be coming from a State that has representation so caring about people who need that kind of representation. I do thank you.

Senator WEICKER. Thank you. We are proud of you. Thank you very much.

STATEMENT OF HERMAN H. SAMSON, PH.D., ALCOHOLISM AND DRUG ABUSE INSTITUTE, UNIVERSITY OF WASHINGTON

Senator WEICKER. Our next witness is Dr. Herman Samson, of the Alcoholism and Drug Abuse Institute, the University of Washington.

Mr. SAMSON. Mr. Chairman, I am Herman Samson, director of the Alcohol and Drug Abuse Institute at the Warren G. Magnuson Health Sciences Center at the University of Washington in Seattle. I am also a member of the Research Society on Alcoholism, whose common interest is the development of knowledge applicable to the detection, prevention, and treatment of alcohol abuse and alcoholism.

It is the only professional society in the field of alcohol research. I am pleased to appear before this subcommittee to represent the concerns of its membership regarding the President's proposed fiscal year 1989 appropriations for the National Institute on Alcohol Abuse and Alcoholism.

I am sure that you are aware that the ever-increasing extent to which alcohol is implicated is a contributing factor in social and medical problems. Alcohol's actions have been found not only to potentiate risk for pathological conditions such as cancer and heart disease, but also to underlie a majority of pressing social problems such as violence, rape, and child abuse.

It appears that in many cases alcohol also serves as the gateway drug to the use of other substances.

While it was initially thought that alcohol acted only to introduce individuals to social drug use, it has recently been shown that alcohol exerts some of its actions in the brain by mechanisms similar to those of heroine, cocaine, and the amphetamines.

The National Institute of Medicine's recent report to Congress on alcohol abuse documents our understanding of the roles which both genetic and environmental factors play in abuse and which has greatly expanded in the past 10 years. It is through this understanding gained from research that more effective prevention and intervention strategies will be developed, and it is crucial to provide sustained levels of high support.

There is not time to discuss all of these advances, but as the report indicates, the application of a biobehavioral approach, which combines biological and behavioral sciences, has been very productive.

The rapid advances being made in the field with the discovery of potential genetic and phenotypic markers of alcoholism have enabled the realistic contemplation of large-scale family studies.

Recently a meeting of scientists from several alcohol research centers from around the country met to consider the feasibility of a national collaborative study, and the unanimous conclusion was that it is very timely and important to begin such a study.

The NIAAA views this direction of research as a major new initiative and the RSA is ready to assist in the development of support language to this end.

The President's fiscal year 1989 request for NIAAA provides only $108.2 million, of which $83.1 million would be for research. These amounts are below current service dollars, estimated to be $115.4 and $87.7 million, respectively, and would necessitate curtailment in the number of new and competing grants, as well as cuts in the budgets of ongoing grants.

We believe that this retrenchment occurring at a time when new and exciting advances are being made on a major health problem that affects 18 million Americans and costs the Nation more than $117 billion overall is unwise. Rather, we believe that a substantive increase in alcohol-related research support is warranted.

The Research Society on Alcoholism, the American Psychiatric Association, the American Psychological Association, and other groups are recommending a 1989 budget for NIAAA of $148.8 million and 231 FTE's. This is an increase of $40.6 million and 36 FTE's over the administration's request of $108.2 million and of 195 FTE's.

In addition, RSA supports the professional judgment budget proposed for other ADAMHA Institutes.

Four decades of fruitful sponsorship and quality biomedical research have helped us conquer various diseases and improve our quality of life. Significant advances and fundamental discoveries do not happen by happenstance.

PREPARED STATEMENT

We believe that a sustained increase in funding for alcohol research is not only cost effective in the long term, but deserving in view of the recent gains in knowledge. We urge you to consider increasing funding for alcohol research and training in 1989 as proposed for the above NIAAA as well as providing the professional judgment budget requests for the other ADAMHA Institutes.

Thank you.

Senator WEICKER. Dr. Samson, thank you very much for your testimony. It is greatly appreciated.

[The statement follows:]

STATEMENT OF HERMAN H. SAMSON

I am Herman Samson, Director of the Alcohol and Drug Abuse Institute at the University Washington. I am also a member of the Research Society on Alcoholism, which has an active national membership of more than 600 doctorate level researchers. Our common interest is the development of knowledge applicable to the detection, prevention and treatment of alcohol abuse and alcoholism. It is the only professional society in the field of alcohol research. I am pleased to appear before this Subcommittee to represent the concerns of its membership regarding the President's proposed FY 1989 appropriations for the National Institute on Alcohol Abuse and Alcoholism (NIAAA).

I am sure that you are aware of the ever increasing extent to which alcohol is implicated as a contributing factor in social and medical problems. Alcohol's actions have been found not only to potentiate risk for pathological conditions such as cancer and heart disease but also to underlie a majority of pressing social problems such as violence, rape and child abuse. It appears that in many cases, alcohol also serves as the gateway drug to the use of other substances. While initially it was thought that alcohol only acted to introduce individuals to social drug use, it has recently been shown that alcohol exerts some of its actions in the brain by mechanisms similar to those of both the opiate and stimulant drugs, i.e., heroin, cocaine and amphetamines. If it can be demonstrated that a common mechanism for all drug taking exists in the central nervous system and that alcohol functions through this mechanism, it would suggest that drinking could directly activate these brain reinforcement systems to promote a wide variety of drug taking behavior.

The National Institute of Medicine's recent report to Congress on alcohol abuse documents how our understanding of the roles which both genetic and environmental factors play in abuse has greatly expanded in the last 10 years. It is through this understanding, gained from research, that more effective prevention and intervention strategies will be developed, and it is crucial to provide sustained high levels of support.

There is not time to discuss all of these advances, but as the report indicates, the application of a biobehavioral approach, which combines biological and behavioral sciences, has been very productive. For example, several strains of animals that exhibit differential responses to alcohol have been developed through selective breeding techniques. We have just begun to use these strains to explore how environmental and genetic factors interact to produce excessive drinking. It has been found that in some cases environmental factors can alter ethanol actions, overriding the genetic basis, while in other conditions environment has little effect. These studies will help to clarify the complexity of genetic-environmental interactions and provide important clues to understanding the various types of alcoholics.

It has also been found that alterations in various brain transmitters exist in genetic strains of rats that prefer alcohol, and that the transmitters affected are related to systems in the brain believed to be important for the expression of positive motivation. How these genetic alterations interact with environmental systems remains to be determined, but the use of the biobehavioral approach is making important advances in our understanding of how alcohol alters brain function.

The rapid advances being made in the field with the discovery of potential genetic and phenotypic markers of alcoholism have enabled the realistic contemplation of large-scale family studies, with the view of performing genetic linkage analysis, much in the way that has been done with Huntington's disease, manic-depression and familial Alzheimer's disease. In fact, in the view of medical geneticists, the task may be more readily accomplished with alcoholism than with manic-depression, for example, because of the high degree of familiality. Recently, a meeting of scientists from several alcohol research centers from around the country met to consider the feasibility of a national collaborative study, and the unanimous conclusion was that it is very timely and important to begin such a study. The NIAAA views this direction of research as a major new initiative and the RSA is ready to assist in the development of support language to this end.

The President's FY1989 Request for NIAAA provides only $108.2 million, of which $83.1 million would be for research. These amounts are below current services dollars, estimated to be $115.4 and $87.7 million, respectively, and would necessitate curtailment in the number of new and competing grants, as well as cuts in the budget of ongoing grants. We believe that this retrenchment occurring at a time when new and exciting advances are being made on a major health problem that affects 18 million Americans and costs the nation more than 100 billion dollars overall is unwise. Rather, we believe that a substantive increase in alcohol-related research support is warranted.

The Research Society on Alcoholism, the American Psychiatric Association, the American Psychological Association, and other groups are recommending a 1989 budget for NIAAA of $148.8 million and 231 FTEs. This is an increase of $40.6 million and 36 FTEs over the Administration's request of $108.2 million and 195 FTEs. Of this amount, $102.1 million would be for research. The increase of 40 positions are to alleviate what we see as a serious understaffing in both intramural research and direct operations. The underfunding has resulted in many missed research opportunities in both intramural and extramural research. In addition, RSA supports the professional judgment budget proposal for the other ADAMHA Institutes which would provide $400.0 million for NIMH research, $150.0 million for NIDA research, and $33.0 million for the research training programs of the three Institutes. In addition, RSA supports funding the ADAMHA AIDS research program at $203.1 million, and the homeless initiative at $115.0 million.

The recommended amount for alcohol research proposed above would provide an increase of 10% in the number of research project grants supported by NIAAA from 328 to 359, provide full funding of the alcohol research centers, and provide $5.4 million for a major new genetics initiative to identify the genes that influence susceptibility to alcoholism and its sequelae. It would also provide modest expansion for treatment outcome research, for career research development, for intramural program growth, and for much needed instrumentation and renovation projects in extramural research funding.

Four decades of fruitful sponsorship and quality biomedical research have helped us conquer various diseases and improve our quality of life. Significant scientific advances and fundamental discoveries do not occur by happenstance. They are the direct result of a 40-year partnership between government and research scientists. The members of the Research Society on Alcoholism fully recognize the current need to balance the Federal budget; however, we do not believe that human service programs, including those of ADAMHA, should continue to bear the brunt of further costs. These programs have already been pared to the bone and Congress must now look to alternative means to control the federal deficit. We believe that a sustained increase in funding for alcohol research is not only cost effective in the long term but deserving in view of the recent gains in knowledge. We urge you to consider increased funding for alcohol research and training in 1989 as proposed above for NIAAA, as well as providing the professional judgment budget requests for the other ADAMHA Institutes.

Thank you.

Senator WEICKER. Our next witness is Dr. Carlton Erickson, College of Pharmacy, the University of Texas at Austin. Is Dr. Erickson here?

Dr. Floyd Bloom, of the Scripps Clinic and Research Foundation? He is not here.

STATEMENT OF RONALD L. ALKANA, UNIVERSITY OF SOUTHERN CALIFORNIA SCHOOL OF PHARMACY

Senator WEICKER. Professor Ronald Alkana of the University of Southern California School of Pharmacy?

Mr. ALKANA. I am Ronald Alkana, associate professor of pharmacology and toxicology at the University of Southern California.

It is an honor to have the opportunity to present my views regarding alcohol research before this committee on behalf of the University of Southern California and as a member of the Research Society on Alcoholism.

My testimony will highlight my laboratory's research which focuses on increasing knowledge regarding the mechanisms by which alcohol affects the brain and behavior.

Over the past decade significant advances have helped to unravel the molecular bases of alcohol-induced intoxication, tolerance, and physical dependence. However, it has been difficult to identify cause-effect relationships between these neurochemical and behavioral events, in part due to the nonspecific nature of the molecular actions which are believed to cause intoxication. The nature of these actions precludes classical pharmacological approaches.

In an attempt to circumvent this problem, my laboratory has investigated the use of increased atmospheric pressure, that is, hyperbaric exposure, on the behavioral effects of alcohol in mice.

We have obtained considerable evidence that hyperbaric helium-oxygen gas mixtures represent a direct antagonist of alcohol's molecular actions that can be used to investigate the sequence of events leading from the initial action of alcohol on brain cells to acute intoxication, tolerance, and physical dependence.

By increasing knowledge of the changes in brain function that cause intoxication, we should be able to identify abnormalities in brain function that lead to alcohol-related problems.

Knowledge regarding the biological basis for differences in sensitivity to alcohol has been growing rapidly. Several important overlapping interactive factors for mediating those differences, including genetic background, alcohol metabolizing enzymes, adaptive processes and age have been identified. Results from our laboratory indicate that body temperature during intoxication is also a critical factor.

The findings on this project have important clinical implications. Our results in mice suggest that exposure to hot environments may increase the risk of fatal alcohol overdose in humans at concentrations of alcohol that would not be lethal under normal circumstances.

In addition, body temperature manipulation will represent a simple means of reducing the thousands of lives lost each year from alcohol or alcohol combination overdoses.

My comments today have highlighted some of the important information gained by one research program. Findings of major significance have also been made by other laboratories, as indicated previously. These successes are the direct result of the funding that alcohol research has received in recent years.

However, the war on alcoholism is not won. Considerable more information is needed regarding the mechanisms by which alcohol works, biological basis of the disease, and methods for turning this information into effective treatment and prevention strategies.

Alcohol represents the No. 1 drug problem in the United States, costing over $100 billion annually, yet the Federal resources devoted to alcohol research are disproportionately small. Continued increases in the Federal alcohol research budget are essential if we hope to control alcohol-related problems. The President's recommended $83 million for alcohol research in fiscal year 1989 represents less than eight one-hundredths of 1 percent of the alcohol-related costs and will not maintain current programs.

Therefore, I strongly support the Research Society on Alcoholism's fiscal year 1989 funding recommendation of $102.1 million for NIAAA's research activities.

Thank you for the opportunity to express my views.

[The statement follows:]

STATEMENT OF RONALD L. ALKANA

It is an honor to have the opportunity to present my views regarding alcohol research before the Senate Subcommittee on Labor-HHS-Education Appropriations on behalf of the Research Society on Alcoholism. First, I would like to thank the Committee for supporting alcohol research last year. These funds have attracted a number of new top researchers into the alcohol field and have made possible the beginnings of important breakthroughs that will lead to a better understanding of the causes of alcoholism and the development of more effective methods of preventing and treating alcohol-related problems. I hope that this rate of growth continues. For these reasons, I strongly support the recommendations of the Research Society on Alcoholism requesting $148.9 million for all of the National Institute on Alcohol Abuse and Alcoholism's research, training and direct operations, of which $ 102.1 million would be available for research project grants, center grants and other essential extramural and intramural research activities.

My testimony will highlight the research in my laboratory which focuses on increasing knowledge regarding the mechanisms by which alcohol affects the brain and behavior and will: 1) include the importance of this research in understanding the causes of alcoholism, genetic differences in sensitivity to alcohol and 2) will describe how information regarding the mechanism of action of alcohol should lead to more effective methods of preventing and treating alcohol-related problems.

Over the past decade, significant advances have been made which are helping to unravel the molecular bases of alcohol-induced intoxication, tolerance and physical dependence. However, it has been difficult to identify cause-effect relationships between these neurochemical and behavioral events. Part of the difficulty lies in the non-specific nature of the molecular actions which are believed to cause intoxication. The nature of these actions precludes the classical pharmacological approach of using specialized drugs to study these relationships.

In an attempt to circumvent this problem, one project in our laboratory has studied the effects of hyperbaric pressure (i.e., increased atmospheric pressure) on the behavioral effects of ethanol in mice. Over the past seven years, we have obtained considerable evidence that exposure to hyperbaric helium-oxygen gas mixtures antagonizes a broad spectrum of alcohol's acute and chronic behavioral effects and that the antagonism represents a direct effect of pressure.

One of our most important findings is that hyperbaric exposure antagonizes a wide spectrum of acute and chronic effects of ethanol. The breadth of the antagonism links different acute and chronic behavioral effects of ethanol to a common membrane mechanism. Specifically, our demonstration that hyperbaric exposure antagonizes both the excitatory and depressant effects of ethanol on locomotor activity suggests that the activating and depressant effects of alcohol may result from the same membrane actions of alcohol. Further, our data indicating that hyperbaric exposure can block the development of tolerance and dependence on alcohol supports the hypothesis that functional tolerance and physical dependence reflect adaptive changes to events initiated by the actions of alcohol which induce acute intoxication. These results also support molecular theories of anesthesia which suggest that the behavioral effects of alcohol result from changes in the structure and function of brain cell membranes.

Taken together, these results suggest that hyperbaric exposure represents a direct antagonist of alcohol's molecular actions that can be used, in place of traditional drugs, to investigate the sequence of events leading from the initial action of alcohol on brain cell membranes to acute intoxication, tolerance and physical dependence. By increasing knowledge regarding the changes in brain function that cause intoxication, we should be able to identify abnormalities in brain function that lead to alcohol-related problems. In turn, this information will help to identify specific targets at which drugs can be directed to reduce the social problems, loss of lives and tremendous economic costs resulting from the misuse and abuse of alcohol.

A second project in my laboratory investigates the importance of body temperature in determining sensitivity to the behavioral effects of alcohol. Knowledge regarding the biological bases for differences in sensitivity to alcohol has been growing rapidly. Several important, overlapping, interactive factors have been identified which can play major roles in mediating differences in alcohol sensitivity between individuals. These factors include genetic background, alcohol metabolizing enzymes, adaptive processes and age. Results from our laboratory indicate that body temperature during intoxication represents another of these critical factors that play a major role in determining alcohol sensitivity and can interfere with attempts to investigate and understand alcohol's actions and effects.

One of the most important findings from this project is evidence that body temperature during intoxication may play a major role in mediating genetically determined differences in alcohol sensitivity. These results suggest that changes in body temperature induced by alcohol may confound attempts to use genetic models as tools for studying initial sensitivities to alcohol, the mechanism of action and effects of alcohol and for using these models in the identification of neurochemical or other pathologies that underlie alcohol-related problems in humans.

Our most recent work in inbred strains and selected lines of mice extends these findings to suggest that there may be qualitative differences in the effect of body temperature change on ethanol sensitivity between animals with different genetic backgrounds. Although speculative at this time, these genetically determined differences in interaction between body temperature and ethanol sensitivity may represent a new tool which can be used to separate and/or identify biological mechanisms underlying alcohol's effects.

The results on this project also have important clinical implications. First, they show that increasing body temperature can increase sensitivity to the lethal, as well as behavioral effects of alcohol. This work in mice suggests that humans who become intoxicated and then enter a hot tub may increase the risk of fatal alcohol overdose at concentrations of alcohol that would not be lethal under normal circumstances. In addition, these findings suggest that current protocols used to treat overdose from alcohol or alcohol in combination with other drugs in humans may require modification. These protocols typically ignore body temperature or view the attendant reduction in body temperature as a complication requiring warming of the patient. In contrast, our results suggest that holding body temperature at a sub-normal level may represent a simple, non-invasive means of enhancing existing supportive measures and of reducing the thousands of lives lost each year from alcohol or alcohol combination overdoses.

A new project in my laboratory is investigating the role that benzodiazepine receptors may play in mediating the effects of alcohol. These receptors are part of a complex receptor system which inhibits brain function. Work from our and other laboratories suggests that there may be a functional link between the benzodiazepine receptor system and some, but not all, behavioral effects of ethanol. Further studies should provide clues regarding the involvement of the benzodiazepine receptor complex in mediating the acute and chronic effects of alcohol and may help to identify pathologies in the natural neurochemical schema that may lead to alcohol misuse.

The final goal of understanding and preventing alcohol-related problems has not yet been achieved, but significant progress is being made. The summary presented above highlights important information that has been gained in one research program. Many other findings of major significance have been made in other laboratories. Finally, we are beginning to identify the biological underpinning of alcohol-related diseases.

These successes are the direct result of the increased funding emphasis that alcohol research has received in recent years. However, the war on alcoholism is not won. Considerably more information is needed regarding the mechanisms by which alcohol works, the biological bases of the disease and methods of turning this information into effective prevention and treatment strategies. Alcohol-related problems represent the number one drug problem in the United States. Yet, the federal resources devoted to alcohol research are disproportionately small compared to the over $100 billion dollars alcohol-related problems cost the United States yearly. Continued increases in the federal alcohol research budget are essential if we hope to control alcohol-related problems.

Thank you for the opportunity to express my views.

Senator **Weicker**. Professor Alkana, thank you very much for making the effort to be with us this morning.

Our last witness is Dr. Robert Sokol of the Hutzel Hospital, Detroit, MI. Dr. Sokol is not here.

SUBCOMMITTEE RECESS

The hearing is in recess until tomorrow morning at 9:30 a.m. when we will meet to continue our public witness hearings in Dirksen 124. Thank you very much.

[Whereupon, at 11:15 a.m., Wednesday, June 8, the subcommittee was recessed, to reconvene at 9:30 a.m., Thursday, June 9.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1989

THURSDAY, JUNE 9, 1988

U.S. Senate,
Subcommittee of the Committee on Appropriations,
Washington, DC.

The subcommittee met at 9 a.m., in room SD-124, Dirksen Senate Office Building, Hon. Quentin N. Burdick presiding.

Present: Senators Burdick, Weicker, and Hatfield.

Also present: Senator Grassley.

NONDEPARTMENTAL WITNESSES

Senator Burdick. This morning the subcommittee will continue with the last of 9 days of hearings with public witnesses, with testimony focusing on the programs funded by the Subcommittee on Labor, Health and Human Services, Education and the 14 related agencies.

During these several sessions, the subcommittee will hear testimony from approximately 225 witnesses, the highest number yet to be heard by the subcommittee in a single year. Because of the large number of witnesses, we must request that each witness keep his oral testimony brief. You should be assured that your full statement will be included in the printed record.

In order to help us stay on schedule, we are going to use a green and red light system. When the red light goes on, your 3 minutes have expired. We will need to ask each of you to conclude your remarks when the red light goes on, so that each witness will have a fair and equal opportunity to be heard.

STATEMENT OF HON. J. JAMES EXON, U.S. SENATOR FROM NEBRASKA

Senator Burdick. Our first witness this morning is my good friend and colleague from the State of Nebraska, Senator James Exon.

Just a personal reference, do you play football in Nebraska?

Senator Exon. We intend to play this year, if we can get one more player. We have 10; if we can get 1 more, we will field a team.

Senator Burdick. Maybe we could help you.

Senator Exon. Well, we would appreciate any help we can get, and I would certainly thank and recognize my friend from North

Dakota as certainly an expert in that area as well, and if you have any advice for us, why, we are willing to accept it, Senator Burdick.

Senator **Burdick**. With that, you can proceed.

Senator **Exon**. Thank you.

Let me see if—I think I can be very brief.

Mr. Chairman, I just want to start out by thanking you, the subcommittee and the committee as a whole for the understanding approach that you have taken for many years to the important matter of impact aid. This has particularly important aspects to States the geographical size and the relatively small population size of the North Dakotas and Nebraskas of our great country.

I want to thank you for allowing me to testify on behalf of the Impact Aid Program. As you know, I have strongly supported this program for a long time, and because of my strong support, I have testified several times before this subcommittee urging full funding for this very important program. Nebraska has a wide variation among school districts as to the degree of impaction, impact aid payments are no less important to the lesser impacted schools than to those districts totally or near totally dependent upon impact aid.

Mr. Chairman, earlier this year, Congress passed legislation, H.R. 5, reauthorizing the Impact Aid Program for another 5 years. Although the course of reauthorization was rather tumultuous, at times, the end result is a good, solid piece of legislation that has the support of the entire impact aid community. And that says quite a bit considering the divergent interests of those involved.

H.R. 5 did more than simply extend the Impact Aid Program for 5 years. H.R. 5 basically rewrote the impact aid provisions and brought the language more in line with the true situation today.

However, for this new language to work as intended, the program needs to be fully funded. H.R. 5 sets the authorization level at $735 million for fiscal year 1989.

The new language for impact aid sets up some off-the-top payments to special categories of students such as handicapped students, section 2 districts, and 3(d)(2)(b) districts, districts with populations which are at least 50 percent federally connected, and despite reasonable tax efforts, are still short of sufficient school funds. The remaining funds are then distributed to the regular category A and B students. If full funding is not available, these regular students are going to be short funded.

Mr. Chairman, the program needs $735 million.

In conclusion, then, just let me say there are many other programs deserving full funding, but the most important is the impact aid construction fund. H.R. 5 authorizes $25 million for 1989. This program is seriously underfunded and has been for many, many years. I have one district in Plattsmouth, NE, that is in dire need of new buildings to house elementary students. Just this spring they were finally put on the temporary waiting list, which has over 100 districts on it already. At current funding levels, only one to two projects can be funded a year. At this rate, some schools would have to wait 50 years to get assistance from construction funds.

We desperately need to pump more money into this program.

PREPARED STATEMENT

And so, Mr. Chairman, I thank you for holding these very important hearings, and I appreciate this opportunity to testify.

I would be pleased to try and answer any questions that you might have or other members of the committee might have on this subject.

With that, I thank you.

[The statement follows:]

STATEMENT OF SENATOR JIM EXON

Mr. Chairman, members of the committee, I want to thank you for allowing me to testify today on behalf of the Impact Aid Program.

As you may know, I have strongly supported this program for a long time. And because of my strong support, I have testified several times before this subcommittee urging full funding for this very important program. While in Nebraska we have a wide variation among school districts as to the degree of impaction, impact aid payments are no less important to the lesser impacted schools than to those districts totally dependent upon impact aid.

Mr. Chairman, earlier this year Congress passed legislation, H.R. 5, reauthorzing the Impact Aid Program for another 5 years. Although the course of reauthorization was rather tumultuous at times, the end result is a good, solid piece of legislation that has the support of the entire impact aid community. And that says quite a bit considering the divergent interests of those involved.

H.R. 5 did more than simply extend the Impact Aid Program for 5 more years. H.R. 5 basically rewrote the impact aid provisions and brought the language more in line with the true situation of today.

However, for this new language to work as intended, the program needs to be fully funded. H.R. 5 sets the authorization level at $735 million for fiscal year 1989.

The new language for impact aid sets up some off-the-top payments to special categories of students, such as handicapped students, section 2 districts, and 3(d)(2)(b) districts (districts with student populations which are at least 50 percent federally connected and, despite reasonable tax efforts, are still short of sufficient school funds). The remaining funds are then distributed to the regular category of A and B students. If full funding is not available, these regular students are going to be short funded. Mr. Chairman, this program needs $735 million.

Also deserving full funding is the impact aid construction fund. H.R. 5 authorizes $25 million for fiscal year 1989. This program is seriously underfunded and has been for many, many years. I have one district in Plattsmouth, NE, that is in dire need of new buildings to house elementary students. Just this spring they were finally put on the temporary waiting list, which has over 100 districts already on it. At current funding levels, only one to two projects can be funded a year. At this rate, some schools would have to wait 50 years to get assistance from the construction fund. We desperately need to pump more money into this program.

Mr. Chairman, I appreciate this opportunity to testify. I would be pleased to answer any questions you or other members of the committee may have. Thank you.

Senator **BURDICK**. You and other witnesses have requested for fiscal year 1989, $735 million. The President's request is for $592 million.

I understand the difference is to the elimination of payments for the B children, which is about $130 million in cuts.

Senator **EXON**. Well, Mr. Chairman, let me say I think that would be a grave mistake because while we do have categories A and B, and while it can be certainly justified, in my opinion, that the A's be given some special consideration, there are many, many school districts that have a high ratio of B students that would be devastated if that program were totally eliminated.

Therefore, I would suggest that that should not be an option.

Senator **BURDICK**. Thank you, Senator.

Senator **EXON**. Thank you, Senator.

STATEMENT OF SGT. MAJ. C.A. "MACK" McKINNEY, USMC (RETIRED), LEGISLATIVE COUNSEL, NON-COMMISSIONED OFFICERS ASSOCIATION OF THE U.S.A. [NCOA]

Senator BURDICK. Our next witness will be C.A. "Mack" McKinney, Sergeant Major, U.S. Marine Corps, legislative counsel, Non-Commissioned Officers Association of the U.S.A.

Welcome to the committee, Mr. McKinney.

Sergeant Major McKINNEY. Thank you, Mr. Chairman. I appreciate this opportunity to appear here today on behalf of the Non-Commissioned Officers Association and its membership.

Mr. Chairman, I do not pretend that I know nor understand the system of payments under the Impact Aid Program for military children enrolled in local civilian schools and as set forth in the new authorization act. I do know that unless the affected school districts receive adequate funds for both sections 3(a) and 3(b) students, there could be a recurrence of past events. I believe the chairman may recall that some years past, particularly in the Nixon administration, when a number of dollars were rescinded from impact aid, it adversely affected a number of the school districts throughout the United States who had military children enrolled therein.

Some schools, since then, have notified the parents that their children would be unable to graduate, and yet others have notified the parents threatening the resumption of impact aid payments which, if it did not occur, would cause more adverse actions. However, many of these schools have been taken to court, and the threat of those tuition aid fees have vanished or they have resumed the primary task of educating those military children.

Now, our association is fearful that unless Congress fully funds this $735 million authorized for both 3(a) and 3(b) students, there will be another resurrection of the ills experienced within the earlier years. Hopefully this distinguished subcommittee will take the proper action and recommend the $735 million appropriation.

PREPARED STATEMENT

Though I do not believe the distinguished chairman needs to be reminded of this, it might be in the best interests that the record reflects that our military families now are part of the All-Volunteer Force adopted by this Congress. It is therefore, we believe, the duty of the Federal Government to ensure that our military children are educated as well as any other child in these United States.

Thank you, Mr. Chairman.

Senator BURDICK. Thank you for your testimony.

Sergeant Major McKINNEY. Thank you, sir.

[The statement follows:]

STATEMENT OF SGT. MAJ. C.A. "MACK" McKINNEY

MR. CHAIRMAN: The President's budget request for funding the FY 1989 Impact Aid programs under Public Law 81-874 and Public Law 81-815 is $592 million. This amount includes $557 million for maintenance and operation activities under Sections 2 and 3, $10 million for disaster assistance, and $25 million for construction projects.

Of primary interest to NCOA is the maintenance and operation funds. $547 million is requested for Section 3(a). This money will be used to make payments to school districts that have enrolled dependent children of military personnel and civilian employees who live and work on federal property and do not pay local taxes.

Not included in the President's request are funds for Section 3(b) students who are dependent children of military personnel and civilian employees working or living on federal property. According to the Reagan Administration these children "create no significant burden for local school districts."

The balance of Section 3 funds, $10 million, is earmarked for increased payments to districts eligible under Section 3(d)(2)(B). These districts are heavily-burdened with federally-chartered children and have not adequate funds to offer educational levels equivalent to comparable districts in their states. None of this money is to be made available for Section 3(b) children.

The original intent of Impact Aid legislation was to provide federal funds to school districts heavily impacted with children of military personnel. Subsequent legislation added others; children of federal employees, Indian children, and children residing in low-income housing. Probably, as a side effect to the add-ons, payments for section (a) and (b) students were reduced to levels that are below 70 percent and 50 percent, respectively, of earlier payments.

The lack of or reduction in impact aid causes adverse relations between local school officials and military families. While some have tried to charge tuition fees, others demand that the Department of Defense take over the responsibility for the operation and maintenance of schools located on or near military installations. However, DoD apparently is not interested. Along with the Department of Education, Congress has ordered the two departments to report on ways and means to transfer Section 6 schools to local districts.

What is of immediate concern to NCOA is the continued loss of funds for Impact Aid while more and more members of the military community marry and have children. Today, more than 50 percent of the force is married or the single parent of a child. As the local schools become ladened with additional military children, school officials are reluctant to use local civilian taxpayers' monies to educate the children of a transient society. And no one can rightfully expect these schools to spend local taxpayer's dollars to teach military children the three Rs. This is a federal responsibility.

So, the need for impact aid - if anything - has increased over the years. However, the need has not been fully answered with a like-increase in appropriated federal funds. Maintenance and operation payments constitute whether there will exist an availability of "unrestricted" education for children of military personnel. Without adequate Section 3 payments impacted school districts may decide to disrupt the orderly practice of providing to the children of military personnel quality education, as in the past, by using threats or intimidation.

NCOA, therefore, urges this subcommittee to provide for the necessary appropriations to fully fund impact aid to school districts at the authorized level of $735 million, pursuant to the provisions of H.R. 5.

Thank you.

STATEMENT OF SHIRLEY OLSON, EDUCATION SPECIALIST, NATIONAL MILITARY FAMILY ASSOCIATION

Senator BURDICK. Our next witness will be Shirley Olson, the National Military Family Association.

Welcome to the committee.

Ms. OLSON. Thank you, Mr. Chairman.

The National Military Family Association, NMFA, welcomes this opportunity to express our views on impact aid. The recent reauthorization of impact aid has changed the priority for distribution of the available dollars in the program. NMFA is very pleased with the necessary changes made in the law. However, if impact aid is not fully funded at the $735 million level, many school districts educating military children will receive absolutely no Federal funding. Not only will these military children be placed at risk, so will all of their civilian classmates.

NMFA is also concerned about Federal funding for Public Law 81-815, school construction. We are fully aware of the budget constraints facing this subcommittee, but we are also aware of the results of the Dole report of September 1987. We have already expressed our concerns to the Armed Services Committees regarding the Department of Defense's responsibility for school construction.

Excluding the DOD section VI schools, there are 114 schools located on 48 military installations educating about 55,000 children which qualify for this 815 funding. Of those school facilities owned by the Department of Education, 53 percent have needs resulting from conditions that threaten the health or safety of the children.

In school facilities owned by the local education authority, one-third have needs resulting from conditions that threaten the health or safety of the children.

In summary, the need for fully funded impact aid has increased, not decreased. Hundreds of thousands of military children as well as the children of their civilian neighbors, may be denied an adequate free public education if impact aid is not properly funded.

PREPARED STATEMENT

In recognition of the Federal Government's obligation to school districts that educate military children, NMFA supports full funding for impact aid in school construction programs.

Thank you.

[The statement follows:]

STATEMENT OF SHIRLEY OLSON

The National Military Family Association (NMFA) is a volunteer, non-profit organization composed of members from the seven uniformed services: active duty, retired, reserve and their family members and survivors. NMFA is the only national organization whose sole focus is the military family and whose goal is to influence the development and implementation of policies which will improve the lives of those family members. NMFA welcomes this opportunity to express our views on Impact Aid.

NMFA appreciates your efforts, Mr. Chairman, and that of the sub-committee for your continued support of Impact Aid. We appear today to again request support for full funding for the program.

Impact Aid was designed to ensure the free public education of military dependents. As Impact Aid has expanded, support for the education of military students has been reduced.

1951 - PL 81-874 implemented the support of education for military children

1953 - The law was expanded to include Civil Service personnel

1958 - The Law was expanded to include Indian students who were transferred from the Department of Interior

1976 - The Law was expanded to include low rent housing students

CURRENTLY, MILITARY CHILDREN COMPRISE ONLY TWENTY-SEVEN PERCENT OF THE TOTAL STUDENTS SERVED UNDER IMPACT AID

Category "B" funding is of particular concern to NMFA. The inclusion of military "A" children in the Impact Aid program has been accepted by the Administration and Congress. NMFA realizes funding for military "A" children is a priority. However, funding for Category "B" has been repeatedly eliminated from the President's budget. PL 81-874 clearly states a commitment:

> Congress hereby declares it to be the policy of the United States to provide financial assistance for those local educational agencies upon which the United States has placed financial burden...

The burden the military "B" student places on the school districts is unique. The presence of a military activity increases enrollment and educational costs. It also reduces state and local tax revenues by:

- removal of property from tax rolls
- loss of personal tax revenues through the Soldiers and Sailors Relief Act
- loss of some sales tax
- loss of property tax from business and industry

CURRENTLY, MILITARY CHILDREN COMPRISE ONLY 20 PERCENT OF THE TOTAL STUDENTS RECEIVING CATEGORY "B" FUNDING

How can an Administration that is committed to "Excellence in Education" deny significant funding for the basic education of an entire category of student?

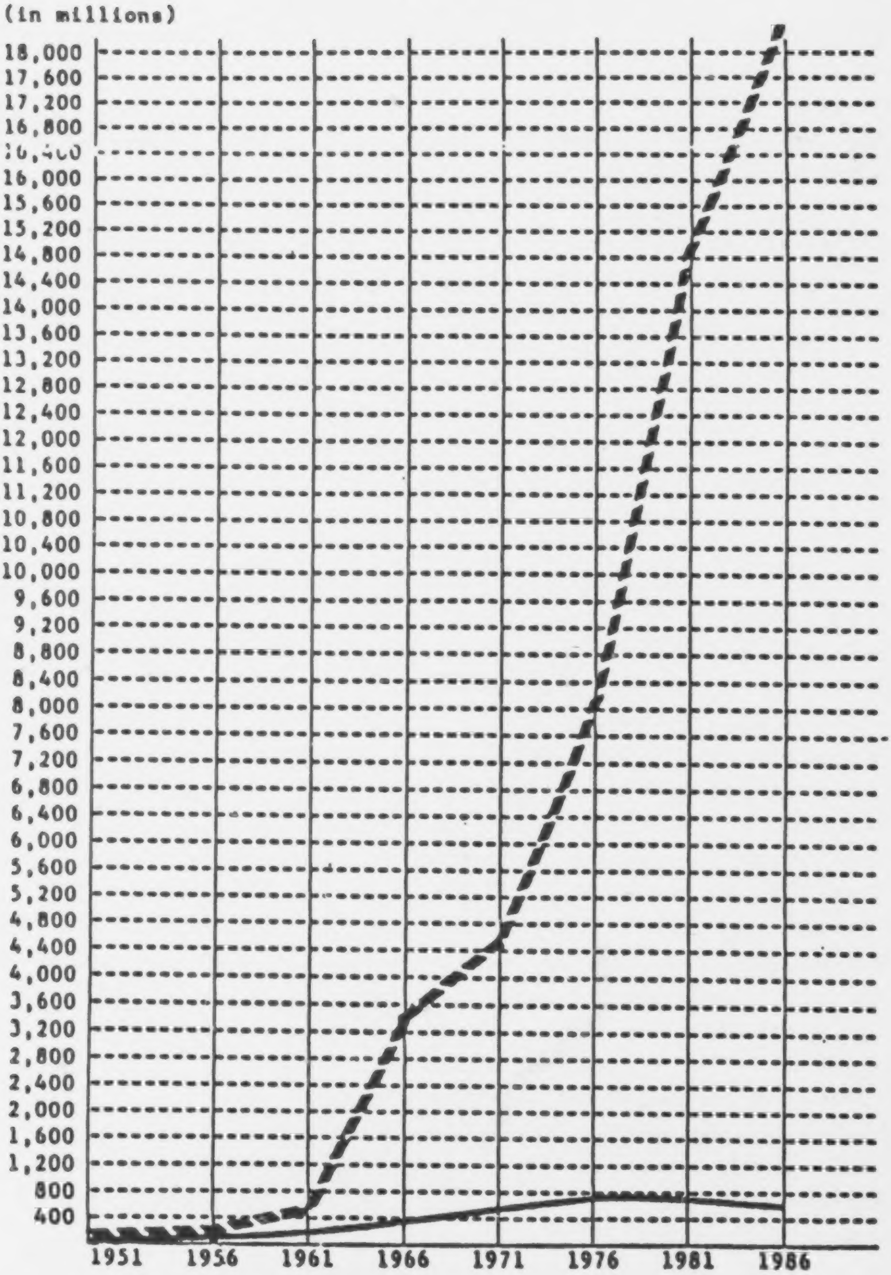
Federal support for Impact Aid has not kept pace with increased program costs (See Enclosures 1, 2 and 3). As a result, many school districts are experiencing difficulty in financing even basic education programs. School districts whose budgets rely significantly on federal support and are highly impacted with military children experience disproportionate hardships. Schools serving military children are the ones faced with closing or curtailing programs when funds run out before the school year ends. Since these schools serve the entire local population, military and civilian, tension and negative relations can develop in the community.

NMFA is also concerned about federal funding for PL 81-815, school construction. We are fully aware of the budget constraints facing this subcommittee. We are also aware of the findings in the Dole Report of September 1987. We have expressed our concerns to the Armed Services committees regarding the Department of Defense's responsibility for school construction. Excluding the DoD Section 6 schools, there are 114 schools, located on 48 military installations, educating 54,800 children, which qualify for 815 funding. Of those school facilities owned by the Department of Education, 53% have needs resulting from conditions that threaten the health or safety of the children. In school facilities owned by the Local Education Authority, one third have needs resulting from conditions that threaten the health or safety of the children. In both categories, 36% have needs generated by enrollment increases that require additional capacity; 24% have needs caused by changes in Federal, State or local laws, standards or regulations.

In summary, the need for adequate Impact Aid has increased - not decreased. Hundreds of thousands of military children, AS WELL AS the children of their civilian neighbors, may be denied an adequate free public education if Impact Aid is not properly funded. In recognition of the federal government's obligation to school districts that educate military children, NMFA supports full funding for Impact Aid and school construction programs

(Enclosure 1)

Appropriation for Impact Aid
Compared to U.S. Education Budget
1951-1987



▬ ▬ ▬ Total U.S. Education Budget

——— Impact Aid Appropriation

SOURCE: MILITARY IMPACTED SCHOOLS ASSOCIATION, INC.

(Enclosure 2)

1981

	L.C.R.	% of payment	Actual Payment	Original Intent of PL 874
Regular A	$959	85	$819	$959
Super A	$959	95	$911	$959
Regular B	$959	38*	$368	$479
Super B	$959	38*	$368	$479

* An extra 5% was added at end of 1981.

1987

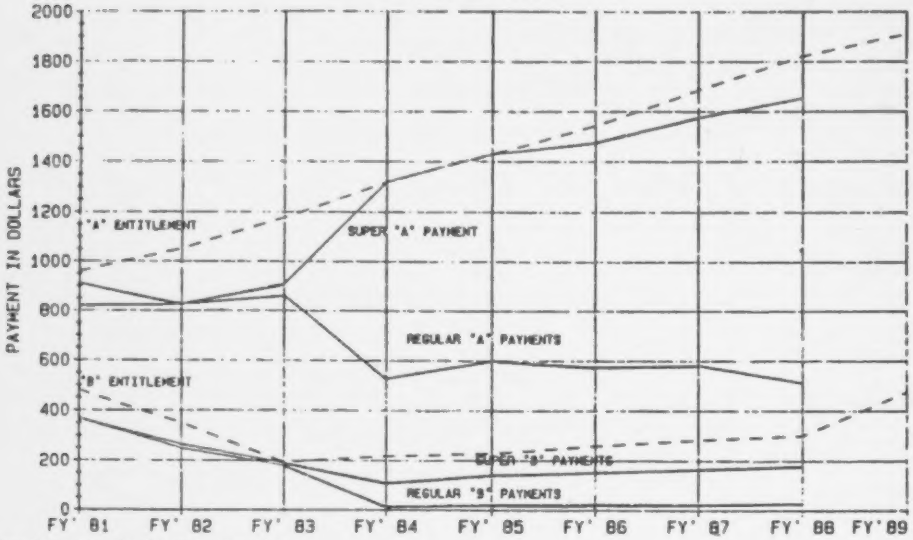
	L.C.R.	% of payment	Actual Payment	Original Intent of PL 874
Regular A	$1686	40% of Super A	$631	$1686
Super A	$1686	limited to 5% growth of 86 payment	$1577	$1686
Regular B	$1686	12% of entitlement	$33	$843
Super B	$1686	60% of entitlement	$168	$843

Source: National Association of Federally Impacted Schools

(Enclosure 3)

HISTORIC PERSPECTIVE OF IMPACT AID PAYMENTS

FY'81 - FY'88



The Committee for Education Funding

Senator BURDICK. Thank you.

The President's request for fiscal year 1989 is $592 million. Witnesses that we have heard so far, including you, put the figure at $735 million.

Ms. OLSON. Yes, sir.

Senator BURDICK. If the President's request for $592 million is appropriated what will be the result?

Ms. OLSON. I feel that, as Sergeant McKinney said, with the priority of funding changes in the new reauthorization, with the handicapped supplement being paid, the section 2 and the 3(d)2(b), with the proration, the amount of funding left for the distribution between 3(a) and 3(b), will force some of the districts, particularly the military districts, to curtail some of their programs. They will not have enough operating funds to keep the schools open. It has happened in the past.

Senator BURDICK. Thank you.

STATEMENT OF DR. NIEL EDMUNDS, PRESIDENT-ELECT, AMERICAN VOCATIONAL ASSOCIATION

Senator BURDICK. Our next witness is Dr. Niel Edmunds, president-elect, American Vocational Association.

Dr. EDMUNDS. Mr. Chairman, I am Niel Edmunds, president-elect, the American Vocational Association.

Today I am representing some 45,000 members in support of the appropriations for the Carl D. Perkins Vocational Education Act.

As our Nation approaches a new century, we face a dilemma. With unprecedented challenges from a global marketplace, the American work force is growing more slowly, becoming older, more female, and more disadvantaged. At the same time, the jobs that are likely to be available to this new sector, require skills that exceed those we are presently preparing the people for.

If nothing is done, a reduction in the American economic leadership and the emergence of a dependent underclass may result. Vocational education programs authorized by the Perkins Vocational Act can help address this dilemma. For fiscal year 1989, AVA recommends an appropriation of $972.6 million for the act. This is some $90 million more than the administration request but it represents only a 2-percent real growth over fiscal year 1987 funding. We believe it is a modest and responsible request.

This year, in sharp contrast to last year's proposal to eliminate funding altogether, the administration proposes to level fund vocational education, but the administration would terminate three programs targeting services to women, families, disadvantaged youth and those with limited English proficiency.

A loss in the number of these students served or in the quality of the training they receive has intolerable implications. AVA believes that the proposal is also shortsighted in disregarding the damage to program quality as a result of erosion by inflation.

Congressional Research Service findings indicate a 31-percent decline in the value of Federal vocational education dollars since 1980. AVA recommends that Congress protect all programs authorized by the Perkins Act from inflation. The three programs the administration would end are now authorized under titles III and IV of the act. One is the assistance for community-based organizations. The youth served by this program are at a high risk of dropping out of school, becoming dependent and contributing to a disadvantaged, unemployable underclass.

Consumer and homemaking education was hardest hit by the administration's proposal. Within the past 20 years, largely due to Federal leadership, it has moved increasingly away from a secondary school program primarily for females to a program serving youth and adults of both sexes. It has been especially effective in the areas of balancing work and family, teen pregnancy, child care, drug and alcohol abuse, and child and family nutrition.

Those with limited English proficiency will constitute an increasing part of our population in the years ahead. These workers must be fully integrated into the labor force, and the bilingual vocational training portion of the act can play a major role. AVA recommends that funds be restored with a modest increase for these programs.

In addition to these recommendations, there are parts of the act which have been authorized but not funded. These are adult training and retraining, career guidance and counseling, and industry education partnerships.

PREPARED STATEMENT

The need for these programs has already been established. It is now time to provide the resources to activate these congressionally approved initiatives.

Thank you for the opportunity to speak to you, Mr. Chairman.

[The statement follows:]

STATEMENT OF DR. NIEL EDMUNDS

I am Niel Edmunds, President-elect of the American Vocational Association (AVA). I am pleased to appear today on behalf of vocational educators — and the more than 19 million students they serve — to support appropriations for the Carl D. Perkins Vocational Education Act. Founded in 1926, AVA is the nation's professional organization with a full-time commitment to help vocational educators and institutions provide effective programs to prepare students for the world of work.

AVA's strength is reflected in its diverse membership of some 45,000 professionals, representing vocational teachers, administrators, researchers, guidance and vocational counselors, and others involved in planning and conducting vocational programs at secondary, postsecondary, and adult levels. Our members prepare students for jobs in fields related to agriculture, business and office education, health occupations, home economics, industrial arts, marketing, and technical, trade and industrial occupations.

But our strength is also reflected in our students, and today, vocational education is almost universal. The First Interim Report from the National Assessment of Vocational Education, conducted by the Department of Education, as directed by Congress in section 403 of the Perkins Act, shows that about 97 percent of all high school students enroll in at least one vocational course and that specific labor market preparation accounts for 63 percent of all vocational coursework. As the Assessment states, "The magnitude of special labor market training may surprise people who think of high school vocational education as consisting primarily of woodshop and other introductory industrial arts courses."A high concentration of secondary school students develop saleable occupation skills and a disproportionate number of these students are from lower socioeconomic strata.

Mr. Chairman, as our nation collectively eyes the approach of a new century and the year 2000, it is clear that we face a dilemma. Lately, a variety of national commissions and committees have documented its immediacy.

Facing unprecedented challenges from a global marketplace, the American workforce is growing more slowly, becoming older, more female, and, of particular note, more disadvantaged. At the same time, new jobs likely to be available in manufacturing and the growing service industry in the year 2000 — jobs vital to our national productivity and competitiveness — will demand higher skill levels than jobs of today. According to the Committee for Economic Development in its report, Children in Need: Investment Strategies for the Educationally Disadvantaged, by the turn of the century, the impact of new technologies is expected to drive total private-sector demand for employment to 156.6 million jobs — nearly twice that in 1978. If these estimates are close, there will be a shortage of over 23 million Americans "willing and able" to work.

But jobs created through new technologies are not the only ones this country will need as it approaches the turn of the century. Labor Department statistics identify computer processing among the fastest growing fields. Nonetheless, in the year 2000 we will need 1.2 million carpenters compared with 580,000 computer analysts. We will need 640,000 electricians and, though the field of agriculture is declining, we will still need 850,000 farmers. The demand for construction trades will grow by 20 percent, with potential to employ nearly 5 million. Simply stated, at a time when America will have new jobs available that it desperately needs to fill to remain globally competitive, its available workforce, desperately in need of employment, may well lack the technical skills necessary to fill those jobs. If nothing is done, the predicted outcome foresees the diminution of American economic leadership and the emergence within America of a dependent "underclass."

Further fueling our dilemma is the fact that one of four youth entering high school today will not graduate. This is most pronounced among disadvantaged and minority youth, who will comprise an increasingly large share of new workforce entrants. The Committee on Economic Development reminds us that "each year's class of dropouts costs the nation more than $240 billion in lost earnings and foregone taxes over their lifetimes." Billions more will be spent on crime control, welfare, health care, and social services.

Federal vocational education programs, as authorized by the Carl D. Perkins Vocational Education Act, can help address this national dilemma. Most recently reauthorized in 1984, the Perkins Act has two basic objectives: 1) increasing the quality of vocational instruction by modernizing programs, and 2) expanding the access to those programs for all persons, but especially the disadvantaged, handicapped, and otherwise underserved. AVA sees the Perkins Act as a model for federal/state/local partnerships, providing effective federal leadership, while distributing more than 90 percent of its aid through state and locally planned and administered programs.

For FY 1989, AVA recommends an appropriation of $972.6 million for the Carl D. Perkins Vocational Education Act. While this is some $90 million more than the Administration has requested, it represents only 2 percent real growth over funding levels in FY 1987. We believe it is a modest and responsible recommendation. It would: 1) maintain current services by accounting for inflation; 2) restore important programs the Administration would terminate, including assistance for community-based organizations serving disadvantaged youth, consumer and homemaking education, and bilingual vocational training; and, 3) provide appropriations for previously authorized but never funded initiatives in the areas of career guidance and vocational counseling, industry-education partnerships, and adult training and retraining.

WHAT THE ADMINISTRATION HAS REQUESTED

For FY 1989, the Administration proposes to "level-fund" vocational education at its FY 1988 level of $881.1 million, in sharp contrast to last year's proposal to eliminate funding altogether. But, in so doing, they would terminate three programs which address critical national priorities by targeting vocational education services to women, families, disadvantaged youth, and those with limited English proficiency.

The Administration's request for continued federal funding, given last year's zero request, speaks well for vocational education's reputation with Congress, and specifically the work of this Committee and its chairman. It is good to be back on the Administration's list of programs deserving federal support.

But it is clear that, as a national priority, vocational education still sits near the bottom of that list. While seeking no growth for "voc ed," the Administration has proposed a 4 percent increase, on average, for other Education Department programs, at least allowing them to escape the slow but sure ravages of inflation. Recently, the Secretary of Education, in prescribing a "model" curriculum for American high schools, made absolutely no reference to vocational education. It is small wonder that those we serve were recently termed by the William T. Grant Foundation as "The Forgotten Half."

By ignoring a projected inflation rate of 4.3 percent, the Administration really proposes a near 5 percent erosion in current federal vocational services. With over 19 million individuals depending on vocational education to learn their livelihood and productivity, a loss in the number of students who can be served or in the quality of the training they receive has intolerable implications both for those individuals and the American economy.

In making its request, the Administration would eliminate three vital programs authorized by titles III and IV of the Perkins Act, while never questioning their effectiveness or offering one word of criticism. An adjustment of about 5 percent would be added to the Title II--Basic State Grant program, seemingly at the expense of the students served by those programs. Current grant recipients under the terminated programs are being told that if they want their programs continued, they need only seek assistance from their state agency which will have additional funds. They are not told that inflation may have "eaten" the additional increase to state grants before their first application is filed. Nor are they told that they may well find their specific programs ineligible for funding under the Basic State Grant program, since the special authorizing provisions in Titles III and IV authorizing their programs have not been proposed for transfer to the Title II authority.

WHAT AVA IS RECOMMENDING

Maintain current services

While applauding the Administration for proposing continued federal funding for vocational education, AVA believes its proposal is short-sighted. It disregards the loss of individuals served and the damage to program quality that inevitably results from the erosion of inflation. The cumulative affect of such erosion is clearly demonstrated by recent Congressional Research Service findings detailing a 31 percent decline in the buying power of federal vocational education dollars since FY 1980.

AVA also applauds the Administration's proposal to provide an increase for the Basic State Grant program; but not at the expense of the programs authorized by Titles III and IV. **AVA recommends that the Congress maintain current services levels for all programs authorized by the Carl D. Perkins Vocational Education Act and provide cumulative funding for FY 1989 in the amount of $972.6 million.** This amount would protect vocational education from inflation, restore those programs targeted for elimination, and allow for modest, responsible growth in several important areas never before funded.

Among programs which should be specifically protected from inflation are the Basic State Grants program, State Councils, and national research, demonstrations, and data systems. The total amount recommended, after inflation is considered, is only 2 percent above the funding level for FY 1987.

Restore Programs Targeted for Termination

As mentioned, the Administration would eliminate three programs critical to our nation authorized under Titles III and IV of the Perkins Act.

Community-Based Organizations Serving Disadvantaged Youth: Assistance for community-based organizations (Title III-A) targets aid to "inner-city youth, non-English speaking youth, Appalachian youth, and the youth of other urban and rural areas having a high density of poverty." These youth are at high risk of dropping out of school, becoming dependent, and contributing to a disadvantaged, unemployable "underclass." Despite the importance of their mission to serve these youth, as set forth in the Perkins Act, community-based organizations, rather than finding their current appropriation of $6.8 million increased, instead find themselves targeted for elimination. **AVA recommends that the Congress fund community-based organizations serving disadvantaged youth at a level of $8.0 million for FY 1989.**

The need to do so is well portrayed by the W.T. Grant Foundation in its recent report, The Forgotten Half: Non-College Youth in America: "Fifty-six percent of black youth live in central city areas .... In addition, disproportionately high concentrations of poverty — in 1985, 43 percent of all black children 18 and under lived in poverty — handicap many of these young people."

The Foundation concludes: "We find that the major unmet needs are for more employment opportunities for at-risk youth and for better quality work experience and closer interaction between work experience and schooling." Vocational education is an obvious answer. It provides both work and school experience, while integrating basic skills.

The Hudson Institute, in its much discussed report Workforce 2000, points to the relevance of targeted vocational training, such as that provided by community-based organizations. The report states that policy makers must find ways to "integrate Black and Hispanic workers fully into the economy." It notes that "the shrinking numbers of young people, the rapid pace of industrial change, and the ever-rising skill requirements of the emerging economy make the task of fully utilizing minority workers particularly urgent between now and 2000. Both cultural changes and education and training investments will be needed to create real equal employment opportunity."

The Forgotten Half specifically cites vocational education's ability to reduce school dropout rates. It finds that many at-risk students who have stayed in school testify that were it not for their vocational courses, they too would have dropped out. "Many at-risk students in vocational classes are motivated to do well because they can see the connection between what they are learning in school and their future success in the real world."

A recent audit of New York City schools, as reported in the March 30 New York Times, validates those findings. It confirms that "New York City's vocational high schools have much lower dropout rates that other high schools but there are too few of them to meet demand." The yearly dropout rate in vocational schools was 4.7 percent, compared with 13.5 percent for students in other schools.

Consumer and Homemaking Education: Consumer and homemaking education (Title III-B) were the hardest hit by the Administration's budget proposal. Within the past twenty years, largely due to the federal leadership, it has moved increasingly away from a secondary school program primarily for females to a program that serves youth and adults of both sexes. It addresses the problems of balancing work and family, teen pregnancy, child abuse, family violence, alcohol and drug abuse, and child and family nutrition.

As these problems reach crisis proportions in some areas of the country and as the need for parenting education becomes increasingly obvious, as the number of school-age parents grows dramatically, it is truly ironic that the Administration would propose terminating this program already active in the school setting. The teachers, classrooms, and students are already in place, with potential to have substantial impact. If consumer and homemaking education did not exist, the Congress would likely create it.

As more women enter the workforce, the need for an environment within the school to teach ways to balance the worlds of work and family has never been more important. According to the Grant Foundation Report, in 1985, nearly 52 percent of married women with pre-school children were working outside the home or actively seeking work, compared with less than 19 percent in 1960. This results from economic necessity. One of four children in married couple families would be poor if they relied only on the father's income.

The Hudson Institute also identifies this as a need, urging policy makers to specifically find ways to "reconcile the conflicting needs of women, work, and families." It estimates that "three-fifths of all women over 16 will be at work in the year 2000."

With too many children depending solely upon their mothers and with far too many mothers being children or teenagers themselves, the need for parenting education is crucial. The Committee for Economic Development lists among its specific strategies for disadvantaged youth "parenting education for both mothers and fathers, family health care, and nutritional guidance." Consumer and homemaking education is active in each of these areas. With the federal leadership supplied through the Perkins Act, that level of activity can be increased. **AVA recommends an appropriation level of $50 million for Title III-B of the Vocational Education Act relating to Consumer and Homemaking Education.**

Bilingual Education and Training: According to Work Force 2000, in the coming years, immigrants will represent the largest share of the increase in the population and the workforce since the first World War. Approximately 600,000 legal and illegal immigrants are projected to enter the United States annually throughout the balance of the century. A just released report, New Voices: Immigrant Students in U.S. Public Schools, estimates that school-age immigrant children constitute 6 percent of the nation's public school enrollment. Non-whites, women, and immigrants will make up more than five-sixths of the net additions to the workforce between now and the year 2000.

The need among Hispanics is especially acute. According to The Forgotten Half, "by the year 2000, Hispanics will be the largest single minority in the general population." They are already one of the youngest, with a median age of 25. Education attainment among Hispanics is far lower than in the general population. Language barriers, an estimated 50 percent adult functional illiteracy rate, and a 40 percent poverty rate among children and youth under age 18 all contribute to lagging educational attainment.

Those with limited English proficiency will constitute a substantial part of our population in the years ahead. By the year 2000, the state of California will likely have a bilingual majority. These workers must be fully integrated into the labor force and bilingual vocational training can play a major role. **AVA recommends that funds for Bilingual Vocational Training be restored at a level of $3.9 million for FY 1989.**

Provide for Responsible Growth in Special Areas of National Interest

While protecting all vocational education programs from inflation and restoring those the Administration would end, there are special programs within the Perkins Act which have been authorized but never funded. The need for these programs is already apparent to Congress, since each area was included in the 1984 legislation. It is now past time to provide appropriations to activate these Congressionally approved initiatives.

Career Guidance and Counseling: Guidance and counseling was identified by James M. Weber in his 1987 study done at Ohio State University as one of three activities which can play an important role in reducing dropouts. The Committee for Economic Development stated: "Few large urban schools have adequate guidance staffs. As a consequence, their time is usually confined to crisis intervention and such activities as special education placement." Employment and career opportunities were specific areas where the Committee said the guidance function for at-risk students needs to be improved.

A variety of information and counseling approaches can expose young people to job opportunities and career options, as well as to successful adult models. These services can be offered both in schools and community settings. They include establishing career information centers, developing the capacity of parents as career educators, and implementing outcome related standards.

The authorization level for career guidance and counseling programs (Title III-D) is only $1 million. Yet, it has never received an appropriation. **AVA recommends an appropriation of $1 million in FY 1989 for Career Guidance and Counseling.**

Adult Training and Retraining: As the average age of the population and the workforce rises, and the pool of young workers entering the labor market shrinks, the need for federal leadership in the area of adult training and retraining is obvious. Adults can now expect to change jobs five or six times during their lives. Now, as states begin to experiment with various basic education, skills, job-training, and remedial education programs as part of welfare reform, the need for innovative demonstrations within vocational education programs is particularly critical. Congress foresaw this need as it authorized Title III-C of the Perkins Act in 1984. Yet, it has never been funded. **AVA recommends a funding level of $5 million for Title III-C of the Perkins Act relating to Adult Training and Retraining.**

Industry-Education Partnerships: The need for business and industry to play an increasing role in education is apparent, especially in vocational education, where job specific training and the molding of vocational curriculum to fit the future manpower needs of business and industry are imperative. But collaboration is still in its infancy. Leadership is needed to provide effective models. Title III-E of the Perkins Act authorizes state assistance for such leadership. **AVA recommends an appropriation of $20 million for Industry/Education Partnership program as authorized by Title III-E.**

Mr. Chairman, that concludes my remarks. In closing, I would like to make a final reference to the W. T. Grant Foundation Report:

> ...a college degree is not the only way to develop the talents of tomorrow's workers. For some, it is far from the best. There are many opportunities outside the college classroom to develop skills and talents and many ways to contribute to a stronger America and to successful personal and family life that do not require a college degree.

AVA strongly supports that statement and sees the Carl D. Perkins Vocational Education Act as the best way to provide the federal leadership necessary to make it a positive reality for American workers instead of a negative stigma for that too often "forgotten half." We appreciate your help.

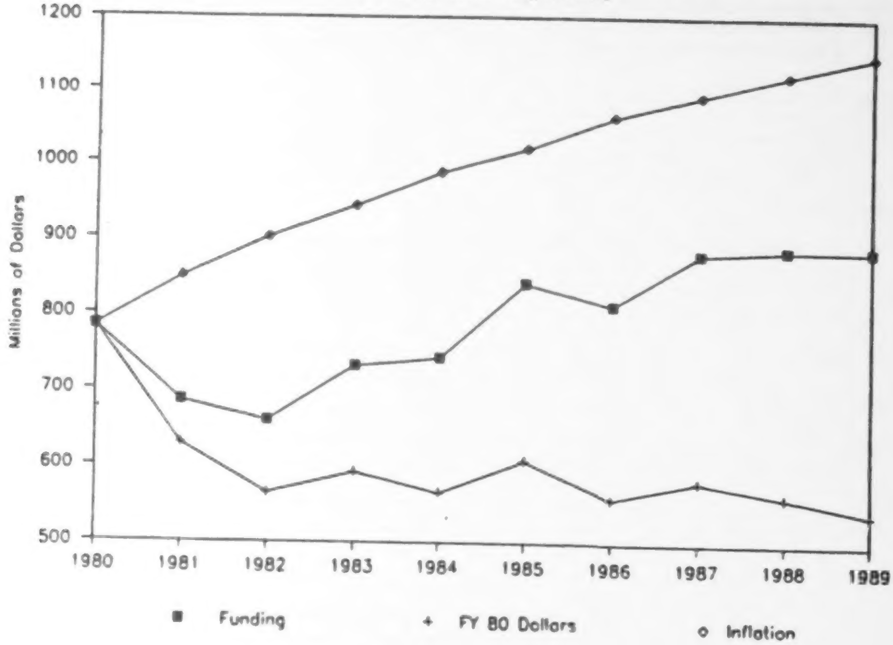
VOCATIONAL EDUCATION FUNDING
(including Smith-Hughes Act)

Fiscal Year	Funding	FY80 Dollars
1980	784,041	784,041
1981	685,599	628,874
1982	659,472	564,006
1983	732,347	591,942
1984	742,731	565,231
1985	842,148	607,429
1986	813,113	557,812
1987	881,967	581,076
1988	888,243	562,116
1989	888,243*	540,408*

Source: Congressional Research Service
Updated Tables for CRS Report for Congress 87-285 EPW

* Administration's Request for FY 1989

Vocational Education Funding 1980–89
(including Smith–Hughes Act)



BUDGET SUMMARY
(In millions of dollars)

	1987	1988	1989 Rqst	AVA Rec.
STATE GRANTS				
Basic Grants	$815.0	$804.2	$848.3	**$848.3**
SPECIAL PROGRAMS				
Community-based Orgs.	$6.0	$6.8	$0.0	**$8.0**
Consumer & Homemaking Ed	$31.6	$32.8	$0.0	**$50.0**
Adult Training/Retraining	$0.0	$0.0	$0.0	**$5.0**
Career Guidance/Counseling	$0.0	$0.0	$0.0	**$1.0**
Industry-Ed Partnerships	$0.0	$0.0	$0.0	**$20.0**
State Councils	$7.5	$7.9	$7.9	**$8.3**
NATIONAL PROGRAMS				
Research	$7.1	$7.3	$7.1	**$7.6**
Demonstrations	$0.5	$14.8	$14.4	**$15.5**
Data Systems	$3.5	$3.6	$3.5	**$5.0**
Bilingual Vocational Ed	$3.7	$3.7	$0.0	**$3.9**
TOTAL	$874.9	$881.1	$881.1	**$972.6**

Senator BURDICK. The substance of your testimony is to increase these various programs by $91.5 million.

Dr. EDMUNDS. Yes, sir; we have been at level funding since 1987, and this really reflects an increase based upon the inflationary rate.

Senator BURDICK. Thank you very much.

Dr. EDMUNDS. Thank you.

STATEMENT OF KERMETA "KAY" CLAYTON, PH.D., ASSOCIATE PROFESSOR AND CHAIR, DEPARTMENT OF FAMILY LIFE STUDIES AND HOME ECONOMICS EDUCATION, UNIVERSITY OF SOUTHERN MISSISSIPPI, HATTIESBURG, MS, AND VICE PRESIDENT, AMERICAN VOCATIONAL ASSOCIATION, HOME ECONOMICS DIVISION

Senator BURDICK. Our next one is Kermeta Clayton, chairman, Department of Family Life Studies and Home Economics Education, University of Southern Mississippi.

Welcome to the committee.

Dr. CLAYTON. Thank you, Mr. Chairman.

My name is Kay Clayton, and I am here as vice president of the Home Economics Division of the American Vocational Association. I am from Hattiesburg, MS. Thank you for allowing me to speak today on behalf of the vocational education community which includes some 50,000 vocational home economics teachers and approximately 3.9 million students in those programs.

We greatly appreciate the support that you have always shown for our programs. We are pleased that the President's fiscal year 1989 budget includes an increase for title II of the basic State grants of the Carl Perkins Act. But we are extremely concerned that the proposed budget eliminates funding for consumer and homemaking education under title III, part B of the act.

As you know, Federal funding for consumer and homemaking education sends a clear message to State and local agencies that these programs occupy a prominent place in education, and specifically, in vocational education. Consumer and homemaking education clearly addresses several national priorities which includes, but are not limited to, economic development and productivity, training special populations, including the disadvantaged and the handicapped, providing programs for at-risk youth, and development of basic skills through applied learning.

It is increasingly clear that productivity is enhanced when workers are able to cope effectively with problems which arise from trying to balance the interrelated responsibilities of family and work. Consumer and homemaking education programs are helping young people and adults develop the skills to achieve this balance. A number of States have developed working family seminars, as Niel mentioned.

In terms of training special populations, the law requires that we spend one-third of the funds for consumer and homemaking education to provide programs in economically depressed areas or in areas with high rates of unemployment. In reality, however, over 50 percent of our funds are used to support such programs.

Another national priority is that of at-risk youth. Consumer and homemaking educators have developed programs which help young people deal with pressures which can develop in teen pregnancy and teen parenting, substance abuse, high dropout rates and sometimes teen suicide.

The priority related to at-risk youth also addresses dropout prevention. We all know that students who complete high school increase their earning capacity, thus increasing their chances of becoming productive, taxpaying citizens rather than welfare recipients.

The 1985 report for the Institute of Educational Leadership by Harold Hodgkinson states that vocational education and work study strategies seem to work well. When the relation between education and work becomes clear, most of these potential dropouts can be motivated to stay in school and perform at a higher level.

Another national priority addressed through consumer and homemaking education is that of integration of basic academic skills. Through assignments and projects, students in consumer and homemaking education develop their reading, writing, and computation skills. Programs in family financial management, consumer education, employability, and nutrition education provide students and their families with skills that they need for survival in today's competitive world, skills such as critical thinking, problem solving, and decisionmaking.

The nature of the work force is changing rapidly, primarily due to advances in technology coupled with the influx of large numbers of women. In today's world, most women find gainful employment an economic necessity. The single parent family headed by a woman is becoming a common family form, and one-half of all families living in poverty today are headed by women.

Even though women have entered the world of work outside the home, they still continue to be the principal homemaker, and thus the need for consumer and homemaking education is critical.

Consumer and homemaking education is a unique art of vocational education in that it addresses the interrelatedness of the home, family, and workplace, programs to prepare both males and females in today's society to assume multiple roles of homemaker, wage earner, and parent.

Research indicates that the connection between work and family is vital to the well-being of individuals and the Nation as a whole. A worker's quality of life greatly influences his or her job satisfaction and productivity, and skills and competencies taught in consumer and homemaking education impact the workplace as well as the home.

I am requesting that line item funding for consumer and homemaking education be restored and increased in the 1989 budget. The Federal dollar is the catalyst is bringing about change, ensuring that programs address national priorities.

PREPARED STATEMENT

Funds appropriated to this program are dollars well spent. Consumer and homemaking education is the only federally funded education program available to our Nation's schools which focuses on improving the quality of life for families. Your continued support will be greatly appreciated.

[The statement follows:]

STATEMENT OF KERMETA "KAY" CLAYTON

My name is Kay Clayton, and I am here as Vice President of the Home Economics Division of the American Vocational Association. I am from Hattiesburg, Mississippi. Thank you for allowing me to speak this morning on behalf of the Vocational Education community which includes some 50,000 vocational home economics teachers and the 3.9 million students in their programs. Almost 300,000 of these students are members of the Future Homemakers of America, Inc., vocational student organization.

We greatly appreciate the support that you have always shown for our programs--especially this past year when funding for vocational education was restored and even increased slightly. We are pleased that the President's FY 89 Budget includes an increase in funding for Title II (Basic State Grants) of the Carl Perkins Act (PL 98-524), but we are extremely concerned that the proposed budget eliminates funding for Consumer and Homemaking Education under Title III, Part B of the Act.

Federal dollars are very important because they generate State and local support to assist states in developing and implementing programs that focus on important national priorities and issues. In most states, elimination of the Federal presence would also mean elimination of Consumer and Homemaking Education programs.

Federal funding for Consumer and Homemaking Education sends a clear message to state and local agencies that these programs occupy a prominent place in education and specifically in vocational education. Federal dollars are the impetus for improving quality and/or updating programs.

Consumer and Homemaking Education clearly addresses several national priorities which include, but are not limited to:

1. Economic development and productivity
2. Training special populations, including the disadvantaged and the handicapped
3. Providing programs for "at-risk youth"
4. Development of basic skills through applied learning

Economic Development and Productivity

It is increasingly clear that productivity is enhanced when workers are able to cope effectively with the problems which arise from trying to balance the interrelated responsibilities of family and work. Consumer and Homemaking programs are helping young people and adults to develop the skills to achieve this balance.

In Ohio, for example, over 2,500 employees in 73 businesses have participated in "Work and Family Seminars" funded with Consumer and Homemaking Education funds. These seminars are designed specifically to increase worker productivity and satisfaction. Similar workshops and seminars have been conducted in many other states, including Minnesota and Mississippi.

Training Special Populations

Historically, Consumer and Homemaking Education programs have served the largest number of disadvantaged and minority persons of any vocational education program. The Law requires that 1/3 of the funds for Consumer and Homemaking Education be spent to provide programs in economically depressed areas or in areas with high rates of unemployment. In actuality, over 50% of these funds are used to support programs which serve youth and adults in areas that are economically depressed or that have high unemployment rates. We might expect this in Mississippi where we have the lowest per capita income of any state and where 1/3 of our children live in poverty. However, Illinois, Iowa, and Minnesota provide shocking examples of what is happening in today's economy in many parts of the country.

Providing Programs for "At-risk" Youth

Another national priority is that of "at-risk" youth. Young people must deal with pressures which can result in teen pregnancy and teen parenting, substance abuse, high drop-out rates, and sometimes teen suicide. Consumer and Homemaking Educators have developed programs to help teens cope with peer pressures. An example is one offered through Ohio's Future Homemakers of America (FHA) organization which sponsors the Teen Advisory Program (TAP) as an intervention to help young people cope with stress and pressure and to prevent teen suicide. In 1985-86, the TAP program reached 13,000 young people.

Florida has also implemented exemplary Consumer and Homemaking Education programs for "at-risk" teenage parents, and these programs emphasize basic academic skills. In Broward County for instance, students attend special centers where they are taught applied academic skills through units in parenting, child development and care, and resource management. They are provided experiences in properly caring for their own children along with others, and they are taught employability skills as well.

Another national priority related to "at-risk" youth is dropout prevention. Like many other states, Ohio has developed programs which focus on enhancement of self-image and self-confidence, homemaking and family living skills, orientation to the world of work, and career awareness. Twenty-one percent (21%) of the 6,500 who benefited from this program in 1985-86 showed improved school attendance, and 26% showed an improvement in their grades. Students who complete high school increase their earning capacity, thus increasing their chances of becoming productive, tax-paying citizens rather than welfare recipients. A 1985 report for the Institute for Educational Leadership, Inc., by Harold Hodgkinson states that

> Vocational education and work-study strategies seem to work well. . . When the relation between education and work becomes clear, most of these potential drop-outs can be motivated to stay in school and perform at a higher level. (p. 12)

Two other "at risk" groups--the very young and the elderly--are targeted in Consumer and Homemaking Education programs. Problems of latchkey children are being addressed in exemplary programs in Florida, Louisiana, Maine, and New Mexico, and Kentucky, while others are found scattered throughout the country. Programs are being implemented which deal with problems associated with aging and the elderly population. The knowledge and skills that students gain in the areas of child development and aging can lead to improved services to these special populations and to increased employability of students in the child care and elder care industries.

Development of Basic Skills through Applied Learning

Another national priority addressed through Consumer and Homemaking Education is the integration of basic academic skills. Through assignments and projects, students in Consumer and Homemaking develop their reading, writing, and computation skills. Computers are utilized in most Consumer and Homemaking programs today, and students are learning to apply new technologies to the occupation of homemaking. Programs in family financial management, consumer education, employability, and nutrition education, provide students and their families with skills that they need for survival in today's competitive world--skills such as critical thinking, problem solving, and decision making.

SUMMARY

The nature of the work force is changing rapidly, primarily due to advances in technology coupled with the influx of large numbers of women. In today's world, most women find gainful employment an economic necessity. The single-parent family headed by a woman is becoming a common family form, and one-half of all families living in poverty are headed by women. Even though women have entered the world of work outside the home, they still continue to be the principal homemaker, and thus the need for Consumer and Homemaking Education is critical.

Consumer and Homemaking Education is a unique part of vocational education in that it addresses the interrelatedness of the home, family, and work place. Programs prepare both males and females to assume multiple roles--homemaker, wage-earner, and parent--in today's society. Research indicates that the connection between work and family is vital to the well-being of individuals and the Nation as a whole. A worker's "quality of life" greatly influences his or her job satisfaction and productivity, and skills and competencies taught in Consumer and Homemaking Education impact the work place as well as the home.

I am requesting that line-item funding for Consumer and Homemaking Education be restored and increased to $50,000,000 in the FY 89 budget. The Federal dollar is the catalyst in bringing about change--ensuring that programs address national priorities. Funds appropriated to this program are dollars well spent. Consumer and Homemaking Education is the only federally-funded education program available to our Nation's schools which focuses on improving the quality of life for families. Your continued support will be greatly appreciated.

Senator **Burdick**. Thank you.

I note that the 1989 budget is calling for $32.8 million, and you are asking for an $11.2 million increase.

Dr. **Clayton**. Yes, sir.

Senator **Burdick**. The President has zeroed it out.

Dr. **Clayton**. Yes, sir.

Senator **Burdick**. If we zeroed out this program, what would be the result?

Dr. **Clayton**. I believe that we will lose programs in our States because the Federal dollar drives the State dollar, and I believe that if the States do not have that Federal dollar, that we will lose a number of programs.

Senator **Burdick**. You would have to drop some of the programs?

Dr. **Clayton**. Yes, sir.

Senator **Burdick**. Well, I know something about the program. We have it in our State of North Dakota.

Dr. **Clayton**. Yes, sir.

Senator **Burdick**. I have heard some good comments about it, and I would hate to see it stopped.

Dr. **Clayton**. Well, I would, too. I believe our students will be the losers if that happens.

Senator **Burdick**. Thank you.

Dr. **Clayton**. Thank you.

STATEMENT OF ALBERTA M. DOBRY, PH.D., C.H.E., CHAIR, DEPARTMENT OF HOME ECONOMICS EDUCATION, NORTH DAKOTA STATE UNIVERSITY, FARGO, ND, ON BEHALF OF THE AMERICAN HOME ECONOMICS ASSOCIATION AND THE COALITION FOR VOCATIONAL HOME ECONOMICS EDUCATION PROFESSIONAL ORGANIZATIONS

Senator **Burdick**. Our next witness will be Dr. Alberta Dobry, North Dakota State University, Fargo, ND, Coalition for Vocational Home Economics Education.

Welcome to the committee, and we are pleased to have you come from our great university to give us some information today.

Dr. **Dobry**. Thank you. It is a pleasure to be here, Senator Burdick.

I would like to begin by saying thanks for this time to speak on behalf of the more than 50,000 home economics teachers represented by the Coalition for the American Home Economics Association, the American Vocational Association and the Home Economics Education Association.

My primary purpose today is to speak to the issue of funding for consumer homemaking education under the Carl D. Perkins Vocational Education Act.

In past years Congress recognized the need to earmark funds when they introduced line item funding for consumer and homemaking education in the act. I am here today to appeal to you to stand behind those original convictions and continue that line item funding.

Based on the successful record of being responsive to socioeconomic changes of families, consumer and homemaking education programs have a great impact on the 3.9 million youth and adults they serve. Our program priority is prevention and alleviation of problems. We help families to successfully manage their money, thus avoiding bankruptcy or preventing a teenage pregnancy, thus avoiding the related costs to child rearing, or assisting the handicapped to function as a productive citizen in society, or improving life skills, attitudes and relationships that make workers more productive. All have long term implications for the family and society.

Besides meeting the needs of the general population, line item funding ensures provision for target programs such as those for school aged parents who might otherwise drop out of school, or for those programs that focus on preventing child abuse such as the one in Bismarck High in North Dakota and many other programs across the country.

It ensures expansion of activities launched by the Future Homemakers of America—that is a cocurricular organization. Their activities range from antidrunk driving campaigns to nutrition education projects where Future Homemakers of America members work with school aged children or with the elderly.

It is line item funding that ensures improvement of programs to prevent drug and alcohol abuse. Success with these programs is increased through a strategy called peer pressure resistance training for students enrolled in those programs. Without line item funding, it would not be possible for continued development of updated materials and provision of inservice education for teachers needed to further increase the success rate of these programs.

The President's budget proposal omits the line item provision set at $50 million for consumer and homemaking education. His budget planners have claimed that line item cuts could be funded under title II of the basic grants. That is unrealistic. With the line item cuts, the level of funding proposed for vocational education barely meets inflationary costs. Further, there are dollar set-aside specifications in the basic grants category that restrict the use of those funds.

PREPARED STATEMENT

The reality is the result would be virtual elimination of funding for consumer and homemaking education. Consequently, Mr. Chairman, we ask that you keep funding for consumer and homemaking education separate from the State basic vocational education grants. Specifically, we ask that you restore the funds for consumer and homemaking education programs in the line item under title III, part B of the Carl D. Perkins Vocational Education Act.

Thank you for your attention.

[The statement follows:]

STATEMENT OF ALBERTA M. DOBRY

Thank you for the opportunity to examine the issue of funding for Consumer and Homemaking Education as part of vocational education. My name is Alberta Dobry. I am from Fargo, North Dakota. Today I am speaking on behalf of the American Home Economics Association and the Coalition for Vocational Home Economics Education Professional Organizations. The Coalition was formed to unite members of the American Vocational Association (AVA), the American Home Economics Association (AHEA), and the Home Economics Education Association (HEEA) and serves to represent more than 50,000 home economics teachers.

The long history of support that you and your colleagues in Congress have given to our programs is very much appreciated. The current Carl D. Perkins Vocational Education Act (P.L. 98-524) includes the legislative specification for Consumer and Homemaking Education under Title III, Part B. As a direct result of previously appropriated funds for Consumer and Homemaking Education, the ongoing work of improving and updating programs has been facilitated to meet the ever changing needs of society. These programs prepare males and females for the occupation of homemaking at all educational levels. Program content is focused on preventive education that addresses national social and economic concerns.

As things stand now, however, these programs are in jeopardy of being eliminated for fiscal year 1989. Part of the President's budget proposal for FY 1989 cuts out all funding for Consumer and Homemaking Education. It is toward this issue that I would like to direct your attention today.

Why would such a sweeping cut be recommended? Could it be because the major concern for funding vocational education is directed toward the work force? If so, then it is prudent for all of us to take note of the fact that productivity in the work force is well documented as being directly related to the quality of home and family life. It is also significant to note here that approximately 77% of today's mothers who have children still living at home are employed at least part time. The manner in which people carry out their dual roles as homemakers and wage earners is a critical factor affecting the degree to which each family member finds family life satisfying. The degree of satisfaction felt within the home in turn affects the attitude and performance of each person on the job. Further, patterns of home living have a direct effect on the mental and physical health of family members. Thus, the skills of homemakers ultimately either directly or indirectly affect the number of days each wage earner loses from work.

In what ways do Consumer and Homemaking Education programs contribute toward productivity and well-being of family members? Specifically, the programs include managing family economics and consumer behavior, managing combined home and work responsibilities, improving responses to individual and family crises (including avoiding family violence and child abuse), strengthening parenting skills, assisting handicapped and aged family members, improving nutrition, conserving limited resources, understanding the impact of new technology on life and work, and applying Consumer and Homemaking Education skills to jobs and careers.

A reinstatement of funding for Consumer and Homemaking Education programs under Title III, Part B of the Perkins Act would not only restore essential dollars but would also send an important message across the nation as well. That is, that families are important and Consumer and Homemaking Education is supported at the federal level as a unique and valuable force in vocational education.

Consumer and Homemaking Education programs developed and operating with current funds have been responsive to socio-economic changes as they affect families. Prevention or alleviation of problems, rather than intervention or remediation, is a program priority. Helping families to successfully manage their money thus avoiding bankruptcy, or preventing a teenage pregnancy thus avoiding the costs related to rearing a child, or assisting the handicapped to function as a productive citizen in society, or improving life skill attitudes that make a worker more productive at paid employment all have long term implications for the family and, consequently, the work force of our society.

Consumer and Homemaking Education programs successfully address some of the most serious problems facing our nation today. Success of a few of the programs aimed at national concerns may be documented by specific examples.

o Teenage pregnancy. Living skills classes by a variety of titles include educational components related to teenage pregnancy. An end-of-the-course evaluation written anonymously by a junior from Devils Lake, ND included the following statement:

> "This class was very informative I thought. Ever since we started this unit it has helped me understand a lot of things I never did before. I have thought about getting pregnant, but I know now that is the absolute wrong thing to do. I'm really glad I picked this class or I could have wound up in the dirt bag. This class helped me realize this."

Attached to that statement was one written by the Consumer and Homemaking teacher of that program. The teacher stated:

> "I strongly believe educating students is the only effective way to reduce or eliminate teen pregnancy and the problems surrounding it. Continued funding of the Consumer and Homemaking Education program will allow more students like the preceding one to have a chance to learn vital facts and examine life goals before making a decision that could change their entire direction in life."

This is merely one of many success stories related to teenage pregnancy. Program outcomes like this occur not only in North Dakota but in Consumer and Homemaking Education programs across the country.

o Child abuse. The significance of dealing with the topic of child abuse in Consumer and Homemaking Education is underscored by the following course evaluation statement written by a senior from Bismarck High School.

> "Through Child Development class I have learned that it is everyone's responsibility, as a human being, to report any suspicion or knowledge of family violence or child abuse. We have a responsibility to the innocent victims who cannot protect themselves from this problem. Consumer and Homemaking classes, such as Family Living, Independent Living, and Child Development have also taught me that parents or family members who abuse children are not inhuman, incurable monsters. They are people with problems and need help solving them. They are sick and need professional help. I have just written a report of suspected child abuse within my family. It causes a great deal of stress and anger in the family, but it's worth it all just knowing an innocent child is being saved."

o Assisting the aged. Several chapters of the Future Homemakers of America (FHA) youth organization, a student leadership organization within Consumer and Homemaking Education, have launched an "adopt a grandparent" project. In conjunction with learning about the aging process, the students become personally involved with an elderly person (or couple) in the community. Members of one FHA chapter shoveled snow for the elderly and spent time visiting after each snowfall. As a result, both age groups grew to understand and appreciate each other more. Other FHA Chapter members have become involved by helping write letters for the elderly who have vision problems or go shopping with the elderly to help open doors and carry packages. In each FHA Chapter most of the relationships established during the special project have voluntarily continued on an independent basis. In several cases the students have decided to pursue careers in working with the elderly as an outcome of their involvement with the FHA project.

o Substance abuse. Teachers of Consumer and Homemaking Education programs have included units on drug and alcohol abuse for over a decade. As more information has become available and teachers have acquired experience with new teaching strategies, their effectiveness has increased. The new emphasis on peer pressure resistance training where students learn and practice resistance techniques and develop personal coping skills has yielded better results than ever before. A student from one of these programs reported that he had been at a party where some of his peers expected him to drink alcohol. "I was sure on the spot," he said. "I don't know what I would have done without that resistance training."

Without funding for the development of instructional materials and provision for teacher education updating, the student in the preceding example and the many others like him might never have received peer pressure resistance training. Can we afford to have funding cut to eliminate preventive education such as this?

There are many additional examples of the positive affect of Consumer and Homemaking Education. It is my hope that the few presented have given you a feeling of the significant impact that the programs have on youth and adults and on the well-being of children, families, and individuals.

Consumer and Homemaking Education programs have great impact on the 3.9 million youth and adults they serve. Consumer and Homemaking Education exists in nearly every community in the country. To insure the continuation of these programs, we ask that you act as you have previously and restore funding for Consumer and Homemaking Education programs under Title III, Part B of the Carl D. Perkins Vocational Education Act. We ask that you do as you have for over two decades and keep funding for Consumer and Homemaking Education separate from the basic grants for general vocational education.

Thank you for your attention this morning and your consideration in the matter of Consumer and Homemaking Education funding.

Senator BURDICK. Thank you very much.

I notice you did some skip reading here.

Dr. DOBRY. Yes.

Senator BURDICK. I want you to be assured that your whole statement will be made part of the record.

Dr. DOBRY. Thank you very much.

Senator BURDICK. Thank you.

STATEMENT OF RUTH GRAVES, PRESIDENT, READING IS FUNDAMENTAL, INC.

Senator BURDICK. Our next witness is Ruth Graves, president of the Reading is Fundamental, Inc.

Ms. GRAVES. Mr. Chairman, thank you for the opportunity to testify on the Inexpensive Book Distribution Program operated by Reading is Fundamental, better known as RIF, under contract to the Department of Education.

It is reported that each year we graduate 700,000 high school students who cannot read their own diplomas. A clue as to why may come from two new polls that show by the time students reach upper elementary school, only 39 percent of them like to read. Numerous studies on the reading problem cite as major parts of the solution motivation to read, reading for pleasures, books in the home, and parental involvement.

The book program accomplishes all of these things, and for children, preschool through high school, succeeds in increasing reading skills, library useage, and the amount children read.

RIF has been very modest in past appropriations recommendations. This year we come with a more realistic request. We respectfully request that for fiscal year 1989 Congress appropriate $10 million for the Inexpensive Book Distribution Program. Inflation has steadily eroded this program since 1980. Between 1980 and 1987, funding for the book program increased 17.8 percent while the general inflation was 36 percent, and more importantly, the cost of books, the major cost of the program, increased by more than 65 percent. For example, in 1981 you could buy the popular book, Ramona, for $1.75. Today it costs $3.95.

As a result, we reach 850,000 fewer children now than in 1980, dropping from 3 million children and 11 million books to just over 2 million children with fewer than 7 million books.

In addition, we turn away more than 1,000 requests for new programs every year. An $8.2 million appropriation, the funding floor established in H.R. 5, would mean dropping another 65,000 children from the program. A $10 million appropriation would permit us to reach 2.6 million children.

An increase to $10 million would not, of course, increase the overall education appropriations, as funds for the book program are derived from a percentage of the total chapter II appropriation. The book program is cost effective, costing the taxpayer only $3.11 per child last year, and it brought in private resources amounting to $3.12 for every Federal dollar invested.

Projects receive only funds for books, none for administration, and are staffed by 86,000 volunteers in 10,000 locations nationwide.

In view of the program's cost effectiveness, its proven track record in getting kids to read, demand for its services and the severity of the problem it helps to solve, Reading is Fundamental respectfully requests Congress to forestall further erosion of its services by appropriating $10 million for the Inexpensive Book Program.

Thank you.

Senator **Burdick**. Thank you.

I probably should tell you that I am an old book man myself. I ran a bookstore in Minneapolis and put myself through college at the University of Minnesota, and in those days, the money was not too plentiful. It was really a joy to see all these children come and get their books. They could not afford new books, so they used the old books.

I understand that there is a lot of change in editions now, is that true, that one book does not carry over to the next year?

Ms. **Graves**. I am sorry?

Senator **Burdick**. Is there a change in the editions of books today? A book produced in 1987, can it be produced in 1988?

Ms. **Graves**. Yes; but the prices keep going up and up and up, and you might be interested in knowing that we brought about 32,000 books to 10,000 kids in North Dakota, and it seems to be having very good results with those kids. We are getting reports back that they are reading a lot more and using the library, and their reading scores are going up.

PREPARED STATEMENT

Senator **Burdick**. Thank you very much. You run a good program.

Ms. **Graves**. Thank you very much, sir.

[The statement follows:]

STATEMENT OF RUTH GRAVES

Reading Is Fundamental (RIF) is pleased to present to this Subcommittee recommendations on the Inexpensive Book Distribution Program (IBDP), now included as a Priority Program in H.R. 5, Chapter 2, Part B, Section 1561(b)(2).)

Congress established the Book Program to help prevent illiteracy by increasing the reading abilities of young people. The Book Program does so with a straightforward approach: planned reading activities underscoring both the joys and importance of reading; letting children choose, to keep, books they want and will read; and involving their parents in the process.

The effectiveness of this approach has found confirmation in numerous recent government, university, and private industry studies. Further evidence comes from educators, librarians, parents and others who have through the years, and with striking consistency, credited the program's achievements in increasing reading skills, library circulation, the amount that children read, involvement of parents and, improved attitudes toward learning.

The program reaches about one in 24 preschool through high school age youngsters in all 50 states, Washington, D.C., and the U.S. offshore possessions.

On behalf of the millions of youngsters the book program has helped to grow up reading, RIF thanks the Congress—and especially this Subcommittee—for its support in past years.

RIF RECOMMENDS AN FY 1989 APPROPRIATION OF $10 MILLION

RIF has been very modest in past appropriations recommendations. For FY'89 we place before the Congress a more realistic request—one that will maintain current services, help stem the steady erosion of the program, and meet in some small part, the demand for its services.

We respectfully request that Congress appropriate $10 million for Fiscal 1989 for the Inexpensive Book Distribution Program. We do so for the following reasons:

O Between 1980 and the present there has been a steady decrease in the number of children served as a result of the disparity between the inflation rate and funding for the Book Program. Today the program serves 850,000 fewer children than it it did 1980.

The IBDP appropriations since 1980 have been: FY'80, $6.5 million; FY'81, $5.85 million; FY'82, $5.85 million; FY'83, $5.85 million; FY'84, $6.5 million; FY'85, $7 million; FY'86, $6.698 million; FY'87, $7.8 million; and FY'88, $7.659 million.

O Thus, from 1980 to the FY'88 appropriation, funds for the Inexpensive Book Distribution Program have increased by only 17.8% (according to Congressional Budget Office figures). The general inflation during this period has been 36%. Even more significant for the Book Program is the rise in book costs - the major cost of this program. Surveys show that since 1980, book prices have increased 8% to 13% each year—or something well over 65% for the period. For example, a popular children's book, Beverly Cleary's Ramona cost $1.75 in 1981, but carries a price tag of $3.95 today.

In 1980 RIF brought 11 million books to 3 million children. Today it brings only 6.8 million books (4.2 million fewer than in 1980) to 2,150,000 children.

O Independent studies from the period since 1980 repeatedly underscore the soundness of the

IBDP method, emphasizing the vital role of books in the home, parental involvement, leisure reading, and motivation in increasing reading ability. These elements have been singled out in studies by the National Assessment of Educational Progress, Educational Testing Service, Department of Education, Commission on Reading, and others. They are all components of the IBDP.

O Meanwhile, mounting evidence of the IBDP's success, along with the influential research, lead to an overwhelming demand for the Book Program. Between July and December of 1987 alone, RIF had to deny, for shortage of funds, requests for more than $1.6 million—in just this six-month period. And each year, for lack of funds, we discourage an average of 1,200 groups from even applying. A Ft. Myers, Fla. School Board Member has, like many others, written urgently: "I have a waiting list of schools wanting to be included in RIF, if additional funds could be used for that purpose."

O H.R. 5 establishes a funding floor of $8.2 million for the IBDP. A FY'89 appropriation of $8.2 million, would result in withdrawal of services to some 65,000 children. It will take $8.4 million just to maintain the current services level.

A $10 million appropriation would help restore at least a portion of the loss since 1980, allowing RIF to reach 2.6 million children.

It should be noted that a $10 million IBDP appropriation would not increase the overall education appropriation, as funds for the IBDP derive from a percentage of the total Chapter 2 monies.

Most children who go to school learn the basics of how to read. Yet, according to recent reading assessments, an unacceptably high percentage reach adulthood with, at best, minimum literacy skills:

o Nearly 13% of 17-year-olds still in school are functionally illiterate, and 44% are marginally literate.

o The U.S. Department of Education says that as many as three out of five high school graduates require remedial work; and 9 out of 10 colleges find it necessary to offer remedial English courses to incoming freshmen.

o Our high schools graduate 700,000 functionally illiterate young people every year—and another 700,000 drop out. (Among students who drop out, approximately 60% are functionally illiterate. By contrast, Japan has the highest rate of school completion and literacy in the world—close to 100%.)

The recent studies on achieving literacy include these findings:

O "Books should be a part of every child's life. They should occupy a central place in home and classroom alike....Youngsters need ready access to books...it is of critical importance that boys and girls acquire the habit of reading." ("First Lessons," 1986)

O "Children improve their reading ability by reading a lot. Reading achievement is directly related to the amount of reading children do in school and outside." and "Another key to promoting independent reading is making books easily available to children...." ("What Works," 1987)

O "Children should be encouraged to read for the fun of it....When children are allowed to choose their own books, and are encouraged to read them as a leisure time activity, children read more and improve their reading." ("Becoming a Nation of Readers," 1988)

RIF, through the Book Program, provides the only nationwide, massive, concerted campaign to place books in the hands of children—books of their own choosing to take home, to keep, and to read—while offering programs to encourage them to read those books.

In its 21-year history, RIF has placed more than 85 million books into the hands of children. Of these, youngsters have come to own 79 million books through the IBDP.

THE IBDP GETS CHILDREN TO READ

"Reading Is Fundamental places reading and a love of books in its proper educational perspective. No national program has the potential of more value to children than RIF." (Carl Scholz, Superintendent of Schools, District of Sevastopol, Sturgeon Bay, Wis.).

From Oregon City, Oregon: "Reading test scores have continued to improve steadily throughout the years we have had RIF. Students really like having their own books."

And from Broad Brook, Conn.: "RIF has helped change the attitudes of children in our schools toward reading. Reading scores rose last year and children are sharing books and reading more for pleasure."

Surveys, assessments and studies conducted on the IBDP bear out the kinds of results reported in these typical comments.

The IBDP provides an effective tool for parents, schools, libraries, juvenile detention centers, day care programs, boys and girls clubs, and others to get children to read. The program is adaptable to virtually any setting where children congregate. Activities to motivate reading and personal book ownership are two basic principles maintained throughout the RIF network of 10,000 programs operating under the umbrella of 3,228 local organizations. Beyond that, it is the local citizens who make all the important programmatic decisions: which children to serve, activities to provide, and books to purchase.

Some 86,000 unpaid volunteers operate RIF projects. The projects receive Federal funds only for the purchase of books—none for administrative costs. They provide private funds as a local match to buy books. To help keep down the costs, RIF has negotiated nationwide book discounts with 355 book suppliers.

As a result, last year the program cost the taxpayer only $3.11 per child.

Moreover, the Federal funds have leveraged widespread private support—amounting to $3.12 in private funds, goods and services for every $1.00 appropriated for the IBDP.

Moreover, with private support, Reading Is Fundamental augments the IBDP with wide-ranging services, including: a nationwide at-home winter reading program; a college scholarship competition based on reading; pilot reading programs to reach "at-risk" families; and at-home reading publications and workshops for parents. Workshops have been held in Daytona and St. Petersburg, Fla.; Holmen, Wis.; Hartford and New Haven, Conn.; Albuquerque, N Mex.; Somersworth, N.H.; Lancaster and Philadelphia, Pa.; and 21 other cities.

A LEGACY OF LITERACY

We have cited a few statistics on America's literacy problems. To put those statistics in perspective: the children in school today will, within this century, become our nation's engineers, teachers, factory workers, civil servants. They will be tellers and programmers in our banks, handle our credit card transactions, repair our cars, and affect every aspect of our social, governmental, and financial lives. If large numbers lack adequate literacy skills, the implications for the nation, and each of its citizens, are enormous.

Studies, surveys, economic analyses, and common sense point to the absolute necessity of breaking the cycle of illiteracy.

It is a problem that admits of a solution. As Assistant Secretary of Education Chester Finn recently observed: "The surest cure for illiteracy is the prevention of more illiteracy, and the surest way to do that is to make sure all kids coming out of school know how to read."

Although an infinitesimal part of the Federal budget, the Book Program offers a proven, low cost, and sound means for the Congress to invest in breaking the illiteracy cycle.

BECAUSE:

O Since 1980 there has been a steady erosion of this proven program as inflation outpaced appropriations;

O During this same time, a spate of studies have verified the validity for the IBDP approach;

AND BECAUSE THE BOOK PROGRAM:

O Gets children to read better and often, to use the library more, and gets their parents involved in their education;

O Addresses the compelling problem of illiteracy;

O Offers communities a practical and effective means to get their children to read;

O And is more and more in great demand nationwide (RIF could easily fund $20 million a year to local groups for the IBDP);

READING IS FUNDAMENTAL RESPECTFULLY REQUESTS THE CONGRESS TO SPECIFY AN APPROPRIATION OF $10 MILLION FOR THE INEXPENSIVE BOOK DISTRIBUTION PROGRAM.

STATEMENT OF THOMAS OLSEN, DIRECTOR OF PUBLIC AFFAIRS, U.S.ENGLISH

Senator BURDICK. The next witness will be Thomas Olsen, director of public affairs of U.S.English.

Mr. OLSEN. Thank you, Mr. Chairman.

Linda Chavez, our president, who was supposed to be here today, unfortunately was unable to attend, so I am taking her place.

U.S.English is a 354,000 member national organization that believes that the ability to speak English is of immeasurable benefit to native born Americans or immigrants who seek economic opportunity and ultimately full political participation in this country.

Our organization has, for the last 5 years, tried to make legislators aware that the well intentioned efforts to make the native language services available to immigrants in everything from education to voting, may actually be impeding the full integration of immigrants into the new society.

I would like to state the U.S.English position on bilingual education. U.S.English advocates the provision of special assistance to children of limited english proficiency. But that assistance should be short term and transitional, and the choice of teaching method should be freely chosen by the local school district. The recently authorized Bilingual Education Act makes at least two substantial changes which are of interest to this committee. The most important change is that more funds are now available to a greater variety of teaching methods. Prior to the reauthorization, 96 percent of the funds granted to local education agencies had to be used for transitional bilingual education. The remaining 4 percent of the funds was available to other methods of instruction such as English as a second language and structured immersion.

The act has now been changed to allow 25 percent of the funds to be used for these alternative methods.

A second major change in the law is the addition of the 3-year exit provision. This encourages local school districts to use Federal funds to help students become proficient in English quickly and efficiently.

There are many methods of instruction for limited English proficient children, and there is no one best method. Recent research supports this assertion.

In considering the appropriations level for the Bilingual Education Act for 1989, the committee should keep in mind that this act is but one of many Federal programs providing assistance to persons of limited English proficiency. The Congressional Research Service found nine Federal programs spending $735 million in fiscal year 1987, of which the Bilingual Education Act contributed $143 million to the total.

Obviously we are spending a lot of money to help people learn English in the United States, and well we should. There are many who need the assistance. With today's tight budgets at the Federal, State, and local level, there simply is not enough money to meet all of the Nation's needs to assure that those who need to learn English can do so.

That makes it imperative that the money we do have for bilingual education be spent in the most efficient and least costly manner possible.

U.S.English recommends funding the Bilingual Education Act of 1989 at the same level as 1988. By closely monitoring the results, Congress should have a good sense, within a year or two, of the benefits of the new funding formula and the 3-year exit provision which are found in the reauthorization bill. If the new flexibility is not working, then throwing more money at the problem helps no one. On the other hand, if the new flexibility is working well, especially the funding that is not tied to transitional bilingual education, then Congress may want to consider increasing the 25-percent ceiling on non-TBE programs. The reauthorization bill emphasizes program evaluation to determine in the simplest terms what works and what does not. I suggest that the evaluation is crucial.

I have talked to some of the bilingual teachers in Los Angeles, and there are some positive stories. The teachers by and large are trying hard, but there are also some horror stories about methods of determining who should or who should not be in the bilingual education program.

With the future of so many children at stake, and with the future of our common language before us, we cannot afford many big errors.

PREPARED STATEMENT

In closing, Mr. Chairman, I want to assure you that U.S.English and its members across the country intend to play a constructive role in the continuing dialog on bilingual education. We are hopeful that the reauthorized Bilingual Education Act with carefully appropriated moneys by this committee, will see more limited English proficient children quickly learning English so that they can be part of the main stream of our society and realize the full potential of living in the United States.

Thank you.

Senator BURDICK. Thank you.

[The statement follows:]

STATEMENT OF LINDA CHAVEZ, PRESIDENT, U.S.ENGLISH

I am Linda Chavez, President of U. S. English. I am pleased to appear before the Committee today to testify on the fiscal year 1989 budget request for the Bilingual Education Act and related programs.

U.S.ENGLISH, a 354,000 member national organization, believes that the ability to speak English is of immeasurable benefit to the native born American or immigrant who seeks economic opportunity and ultimately full political participation in this country. Our organization has for the last five years tried to make legislators aware that well-intentioned efforts to make native language services available to immigrants in everything from education to voting may actually be impeding the full integration of immigrants into their new society.

I would like to state the U.S.ENGLISH position on bilingual education: U.S.ENGLISH advocates the provision of special assistance to children of limited English proficiency. That assistance should be short term and transitional, and the choice of teaching method should be freely chosen by the local school district.

The recently-reauthorized Bilingual Education Act makes at least two substantial changes which are of interest to this Committee. The most important change is that more funds are now available to a greater variety of teaching methods. Prior to the reauthorization, ninety-six percent of funds granted to local education agencies had to be used for "transitional bilingual education." The remaining four percent of the funds was available to other methods of instruction, such as English as a Second Language and structured immersion. The Act has now been changed to allow twenty-five percent of the funds to be used for alternative methods.

A second major change in the law is the addition of a three-year exit provision. This encourages local school districts to use federal funds to help students become proficient in English quickly and efficiently.

There are many methods of instruction for limited English proficient children, and there is no one best method. Recent research supports this assertion.

The Dade County Bilingual Curriculum Content Pilot Projects Final Report published results of a comparison between limited English proficient children enrolled in a program in which course content was taught in the native language and a program in which course content was provided in English, using a structured immersion approach. After three years, there was no difference in the pattern of achievement between the different groups of students. There was no discernible advantage to teaching children in native languages. Moreover, researchers found that exceptionally bright children were exited from both programs within a year, and tended to received higher scores on the standardized tests than students who were in the native language classes for two or three years.

In El Paso, a comparison is under way to determine if a program of bilingual immersion was as effective as a program of transitional bilingual education. Achievement was measured by scores on the Iowa Test of Basic Skills, a test commonly used to exit students from many bilingual programs throughout the nation. An Interim Report, released in 1987, revealed that bilingual immersion students outscored transitional bilingual education students in the subjects of reading and language at every grade level. Immersion students scored as high as transitional bilingual education students in mathematics.

In considering the appropriations level for the Bilingual Education Act for 1989, the Committee should keep in mind that this Act is but one of many federal programs providing assistance to persons of limited English proficiency.

The Congressional Research Service, at the request of Congressman Harris Fawell, enumerated the various federal programs that assist in the education of limited English proficient individuals, and estimated the funding levels. A copy of the report is attached. The CRS found nine Federal programs spending $735 million in fiscal year 1987, of which the Bilingual Education Act contributed $143 million to the total.

And this does not include the appropriation of $1 billion per year to assist states to cope with the new alien legalization program, of which an unknown quantity will be devoted to the teaching of English and assimilation efforts.

Obviously, we are spending a lot of money to help people learn English in the United States, and well we should. There are many who need the assistance.

With today's tight budgets at the Federal, state, and local level, there simply is not enough money to meet all of our Nation's needs to assure that those who need to learn English can do so. That makes it imperative the money we do have for bilingual education be spent in the most efficient and least costly manner possible.

The message is clear: Let us improve the ways existing funds are spent so that our schools and our children receive the best services that we can get for our dollar. This means taking the new directions offered in the reauthorized Bilingual Education Act; making federal monies available to the local programs that work best for each individual school district; and assuring that those funds are primarily used to help children learn English and enter the American mainstream.

U.S.ENGLISH recommends funding the Bilingual Education Act in 1989 at the same level as 1988. By closely monitoring the results, Congress should have a good sense, within a year or two, of the benefits of the new funding formula and the three-year exit provision which are found in the reauthorization bill. If the new flexibility is not working, then throwing more money at the problem helps no one. On the other hand, if the new flexibility is working well, especially the funding that is not tied to transitional bilingual education, then Congress may want to consider increasing the 25 percent ceiling on non-TBE programs.

The reauthorization bill emphasizes program evaluation to determine, in the simplest terms, what works and what does not. I suggest that evaluation is crucial. I have talked to some bilingual teachers in Los Angeles. There are some positive stories, and the teachers, by and large, are trying hard. But there are also some horror stories about methods of determining who should or should not be in bilingual education programs. With the future of so many children at stake, and with the futureof our common language before us, we cannot afford many big errors.

There is one additional provision of the new education bill which I would like to mention. The bill creates a new program of English literacy grants which will go to the states for the establishment, operation, and improvement of English literacy programs for individuals of limited English proficiency. I am especially pleased by the program element which sets aside 50 percent of the state granted funds for use by community based organizations with the capacity to administer English proficiency programs.

U.S.ENGLISH is already--through private funds--teaching English to immigrant adults in Southern California through Project Golden Door.Project Golden Door, now nearly a year old, sponsors radio broadcasts of English lessons and is distributing more than 4,000 video tapes on survival English. We also send English teachers to job sites and advertise the availability of English lesson throughout Southern California.

In closing, Mr. Chairman, I want to assure you that U.S.ENGLISH and its members across the country intend to play a constructive role in the continuing dialogue on bilingual education. The existing bilingual education programs, many of which are ripe for change. We are hopeful that with the reauthorized Bilingual Education Act and with carefully appropriated monies by this Committee, we will see more limited English proficient children quickly learning English so they can be part of the mainstream of our society and realize the full potential of living in the United States.

STATEMENT OF EILEEN D. COOKE, ASSOCIATE EXECUTIVE DIRECTOR, AMERICAN LIBRARY ASSOCIATION

Senator **Burdick**. The next witness is Eileen D. Cooke, American Library Association.

Welcome to the committee.

Ms. **Cooke**. Good morning, Senator.

Thank you for this opportunity. We have been here several times in the last 6 or 7 years. We have the same message, urging this committee to reject the administration's recommendations for zeroing out Federal library programs. This year they have a slightly different approach; they are recognizing at long last that there is a Federal role, but they are proposing a whole new approach and nothing, of course, is in law yet, so in effect you are again confronted with a zero budget for libraries.

Attached to the end of my statement is a summary of our budget for the last 3 years, with fiscal year 1987 being the basic level. We are in hopes of improving on that level, keeping in mind that last year's funds were cut back drastically.

As each witness comes up, I can identify with them, whether it is on impact aid or home economics or whatever, because libraries are involved in each one of those types of activities. It certainly is true of the Reading Is Fundamental Program.

We have several concerns. A basic one is the funding of the Library Services and Construction Act which I am sure you know aids North Dakota considerably for bookmobile services. Wearing your other appropriations that, under postal appropriations, many of the projects under the Library Services and Construction Act complement what we do in Books by Mail Programs, extending services to the elderly, to the home bound, to people in institutions and in remote areas, in North Dakota and in Minnesota, my own home State. We understand what it means if you are in a remote area and cannot have access to information and, as you know, we now talk about this being the information age, and libraries are bearing the brunt of that.

There was a reference to the increase in the cost of books. We are particularly anxious that the higher education component, title II, be looked at carefully by this committee. Title IIA has not been funded in the last several years, and college and university libraries are very dependent upon their book and periodical collection in order to serve their users.

Since the Higher Education Act was written, book prices have gone from an average of $8 and some cents to $35 and some cents. Periodical prices have gone right off the charts. They were $8.47, I think, per subscription in 1965, and now they are $77, and several pennies more, so that it is difficult for libraries to really keep up to date on materials. But we also have a new title IID program which would help libraries in the academic area have access to equipment so they could serve their users more expeditiously.

PREPARED STATEMENT

We are in need of training for new librarians coming into the field. By the year 2000, several hundred of our existing librarians will have retired. There is a great shortage of children's librarians.

So once again I want to thank you and the members of this committee for your past support and urge you to keep on helping libraries so we can help your constituents.

Thank you.

[The statement follows:]

STATEMENT OF EILEEN D. COOKE

I am Eileen D. Cooke, Associate Executive Director of the American Library Association and Director of its Washington Office. ALA is a nonprofit educational organization of 45,000 librarians, trustees, educators, and friends of libraries.

The Administration has finally conceded that there is a positive federal role in support of libraries. We welcome the Administration's recognition of the legitimate claim of libraries to a modest level of federal support as a significant change in policy. For all intents and purposes, however, this Subcommittee faces another zero budget recommendation for the current law programs--the Library Services and Construction Act and the Higher Education Act library programs.

ALA appreciates the Subcommittee's strong support of libraries during six years of zero budget requests, and asks that you once again reject the Administration's recommendation of no funding for Department of Education library programs. The attached summary of ALA's appropriation recommendations indicates the full list of programs under your jurisdiction which provide direct benefits to libraries. Our recommendations, for the most part, reflect the amounts needed to restore cuts made late in the FY 1988 funding process, with the addition of a current services factor.

For LSCA, ALA recommends that the cuts imposed in FY '88 in title I services and title VI literacy programs be restored, and that all titles receive a current services adjustment. LSCA supports some of the most innovative programming in public libraries, as well as enabling all types of libraries to share resources across boundaries. For instance, Alaska uses about 72 percent of its LSCA I allotment for service to rural areas or communities without library service. Over 3,000 people per month get service by mail. A number of these families travel more than 100 miles to pick up their boxes of books, or books are flown in to them with supplies. The Southwest Arkansas Regional Library's ELDERCARE project established core lay medical collections in El Dorado, Hot Springs, Hope, Magnolia and Texarkana. The Southeastern Connecticut Library Association developed a model library information delivery system on AIDS involving collection development, materials distribution, programming, and publicity.

In Florida, the Lake County Library System trained county librarians on the selection and use of sci/tech materials for children from 4 to 13 years old, and provided basic sci/tech materials for use by children. In Iowa, the Bettendorf Public Library purchased basic resources for small businesses because of the local loss of industrial jobs and a slump in farming. An LSCA II-funded addition to the Neshoba County Public Library in Mississippi provided space for needed services for the large number of unemployed residents in their search for job materials and information. The Multnomah County Library, Oregon, bought 3,000 paperbacks for use in day-care centers, and assisted day-care workers to improve their skills for reading stories aloud to children on a regular basis.

The HEA II-A College Library Resources grants were amended in 1986 to target grants to the neediest libraries. No academic library can depend on resource sharing for the basic materials needed to support the curriculum. However, the price of published materials has risen faster than overall inflation for some years now. The Consumer Price Index rose 3.7 percent in 1987, but the price of a U.S. hardback book rose 9 percent to $35.35. The price of a U.S. periodical subscription rose 9.9 percent in 1987 and 9.1 percent in 1988, to an average price of $77.93.

HEA II-B funding has been $1 million or less since FY '80. II-B graduate fellowships in library science help to alleviate a growing shortage of librarians due to, according to the "Occupational Outlook Handbook," a drop in master's degree graduates to less than half the level of the middle seventies, and a larger-than-average proportion of librarians who will reach retirement age through the year 2000. Of the approximately 550 faculty in graduate library schools, 15 percent are at retirement age. There are acute shortages of librarians for minority studies and services, of catalogers, of children's librarians, and of school librarians.

HEA II-C has been at $6 million or less for several years. These grants for major research libraries provide assistance in coping with problems such as the "brittle books" phenomenon. Since about 1850, acidic paper has caused one-fourth of research library collections to become so embrittled that further use will result in loss of text. Another, more recent problem is that the sharp decline in the dollar abroad has caused, together with other factors, unusually high price increases for foreign journals, according to a March report by the Congressional Research Service of the Library of Congress. Average cost increases for journal titles from international publishers are expected to be in the 25-30 percent range in 1988.

HEA II-D College Library Technology and Cooperation Grants have elicited an extraordinary response from academic libraries. More than 400 inquiries from potential applicants were received by the Department of Education even before regulations were issued. Draft regulations and an application notice were finally published on March 21. Only about 89 grants are envisioned with initial FY 1988 funding of $3.6 million. Obviously, many more proposals will be submitted than can be funded. High capitalization costs have made it difficult for many libraries to take full advantage of new technology. To more adequately meet the need for the technology necessary to share library resources, we recommend $5 million for FY 1989.

For the ECIA Chapter 2 school block grant, we recommend $575 million. We are pleased to see that school library resources are one of six priority areas to which Chapter 2 funds would be targeted in the newly approved HR 5, reauthorizing elementary and secondary education programs. Without assistance, some schools are hard pressed to replace worn out or lost materials, much less keep up with new books, films, and other media.

The National Commission on Libraries and Information Science has initiated a national campaign to register every child for a public library card. This effort picks up on the recommendation by Secretary of Education William Bennett in "First Lessons"--"that every child should obtain a library card--and use it." Pending legislation would designate September as national library card sign-up month. ALA has joined in this campaign, and strongly supports a budget of $755,000 for NCLIS. Another NCLIS project is the improvement of statistical data about libraries. Through a recent interagency agreement between the National Center for Education Statistics and NCLIS, the two agencies will work with the state library agencies to collect public library data.

The National Center for Education Statistics has enthusiastically supported the development of a public library cooperative data system. During the FY 1981-87 period of stagnant funding for NCES at under $9 million annually, it was difficult for the Center to compile and publish data on all aspects of education, such as libraries. The FY '88 level of $20.9 million, together with committed leadership, has produced noticeable results. ALA strongly supports the budget request of $29,469,000 for FY 1989. We are also very pleased to note that, in HR 5, the public library cooperative data system will be a permanent activity of the newly reorganized National Center for Education Statistics.

The U.S. medical library network depends heavily on the National Library of Medicine as a national resource. The Administration has proposed $74,435,000 for FY 1989, including $3.8 million for a national center for biotechnology information. While this figure appears on ALA's chart, it actually would provide only $70.6 million for continuing NLM operations, a woefully inadequate level. A fiscal 1989 funding level of approximately $95 million would be consistent with the goals and objectives of the NLM's board of regents long-range plan. Funds for the national center for biotechnology information should be increased to $10 million for FY 1989, the figure recommended in legislation that would authorize the center as a separate component within the NLM.

Thank you for the opportunity to present the views of the American Library Association.

SUMMARY OF AMERICAN LIBRARY ASSOCIATION APPROPRIATIONS RECOMMENDATIONS
FY 1989 Labor-HHS-Education Appropriations

Library Programs	FY 1987 Appropriation	FY 1988 Appropriation	FY 1989 Authorization	FY 1989 Reagan Request[1]	FY 1989 ALA Recommendation[2]
Library Services & Construction Act TOTAL	$125,500,000	$125,037,000	$181,000,000	-0-	$132,357,000
Title I, Pub. Lib. Services	80,000,000	78,986,000	95,000,000	-0-	83,360,000
II, Pub. Lib. Construction	22,500,000	22,595,000	50,000,000	-0-	23,544,000
III, Interlib. Coop.	18,000,000	18,669,000	30,000,000	-0-	19,453,000
IV, Indian Libraries	(funded at 2% setaside of appropriations for LSCA I, II, & III)				
V, Foreign Lang. Materials	-0-	-0-	1,000,000	-0-	1,000,000
VI, Library Literacy	5,000,000	4,787,000	5,000,000	-0-	5,000,000
Higher Education Act TOTAL	$ 7,000,000	$ 10,052,000	such sums	-0-	$ 23,294,000
Title II-A, College Lib. Resources	-0-	-0-	such sums	-0-	10,000,000[3]
II-B, Training, Research	1,000,000	718,000	such sums	-0-	1,042,000
II-C, Research Libraries	6,000,000	5,744,000	such sums	-0-	6,252,000
II-D, Technology	-0-	3,590,000	such sums	-0-	5,000,000[4]
VI, Sec. 607 Foreign Periodicals	-0-	-0-	such sums	-0-	1/000,000[3]
Education Consolidation & Improvement Act Chapter 2 El/Sec Educ. State Block Grant[5]	529,337,000	508,439,000	such sums	575,000,000	575,000,000
National Commission on Libraries & Info. Science	660,000	718,000	750,000	755,000	755,000
Center for Education Statistics (incl. library surveys)	8,900,000	20,953,000	such sums	29,469,000	29,469,000
Natl. Library of Medicine (incl. Medical Library Asst. Act)	61,838,000	67,910,000	such sums	74,435,000	74,435,000

[1] Administration will submit $76 million legislative proposal to replace LSCA and HEA II.

[2] ALA generally recommends funding at amounts required to restore FY '88 cuts and adding a current services factor of 4.2 percent.

[3] For currently unfunded HEA library programs, ALA recommends amounts authorized for FY 1987.

[4] Five million dollars is amount authorized for FY '87. Ed. Dept. received over 400 inquiries from potential II-D applicants, even before regs were issued, but estimates awarding only 89 grants from first-time '88 funding of $3.6 mil.

[5] Forward funded consolidation includes former ESEA IV-B School Library Resources and Instructional Equipment.

Senator **Burdick**. I notice a recommendation for $155 million. The administration request is for $76 million. Last year it was $135 million.

Ms. **Cooke**. That is right.

Ten million dollars of our proposed increase would go for the college library program that has not been funded for several years. The legislation was rewritten and targeted to the neediest of institutions with the hope that those funds would be forthcoming. Since it has been rewritten, the title IIA program has not been funded again.

So that would be a reinstitution of that program.

There are two other programs for periodicals under title VI of the Higher Education Act. There is a new program, that has not been funded. We are recommending $1 million to help academic libraries get foreign publications, and the foreign language title under the Library Services and Construction Act which would help Americans become more conversant in overseas activities.

Also, there has been much written about our people working in Embassies abroad that don't know the language and can't really communicate. They are dependent upon the foreign nationals to help them understand and communicate.

So those are two extra programs. I think what we are asking for basically is about $11 million over what we already have for existing programs and we tried to base that on current services level adjustment for inflation.

Senator **Burdick**. I notice here that the amount of money in the request for 1989 is approximately one-half of what we had in 1988.

Ms. **Cooke**. That is right.

Senator **Burdick**. That does not take into consideration these new costs at all.

Ms. **Cooke**. That is our problem, exactly. It is just one-half of what they requested, or what we received, and what they are proposing is to consolidate the Library Services and Construction Act and the Higher Education Act title II program, and they serve different communities. While they complement one another, their purposes are entirely different.

So it is a rather mischievous proposal that they they have laid before us. But I am pleased to say that no Member of Congress yet has seriously considered it. It has not been introduced, and therefore there is really no chance at all that it could be funded, even at that level.

Senator **Burdick**. Well, in reality, what you are asking for 1989 is $20 million over 1988.

Ms. **Cooke**. That is right.

Senator **Burdick**. That is the base of it.

Thank you.

Ms. **Cooke**. Thank you, Senator.

STATEMENT OF GERALD SROUFE, PH.D., DIRECTOR, GOVERNMENT AND PROFESSIONAL LIAISON PROGRAM OF THE AMERICAN EDUCATIONAL RESEARCH ASSOCIATION

Senator **Burdick**. Our next witness is Gerald Sroufe, Ph.D., American Educational Research Association.

Welcome to the committee.

Dr. **Sroufe**. Thank you.

Good morning, Senator.

The American Educational Research Association is a small group with 14,000 members who are those persons and universities primarily responsible for the conduct of educational research.

We appreciate this opportunity to speak with you this morning and in doing so, I would like to abridge my printed remarks and simply make four points, if I might.

One is that statistics are not the same as research.

Two is that more research is in fact needed.

Three is that Federal funding of educational research is woefully inadequate.

And four is that the budget proposed by the administration for education research in 1989 merits the support of Congress.

Congress has done very well in providing for an increased research and statistics capacity, at least at the statistical aspect, and the provisions of the Hawkins-Stafford Act are going to provide even better information. The point that I would like the Senate to consider is that statistical information is only the beginning of the process of developing sound policymaking.

For example, when the National Assessment of Education Progress reveals that we are not doing very well in math, as came out this week, we then have to look at the question of what we might do about it, and the statistical data will not really provide much information there.

What effects are associated with alternative policies is the question that is important to the Congress, and to gain this information, one must seek explanation and understanding, and that is what research sees to provide.

One of the phrases that frequently concludes any research study is that more research is needed. And I know that frequently that is an anathema to policymakers. The point I would like to try to make, is that in sound and serious research, the most reasonable outcome, is that more research is needed.

I present a small vignette in the statement for the record about some research on the impact of kindergarten on children's performance in school, which would seem to be policy relevant given our great interest in early childhood education now. These individual researchers were interested in knowing what happens in kindergarten? Is the impact on children in their social skill development or in their conceptual skills development?

They wanted to know whether the impact was the same for all children or whether it varied according to race, sex, or income level? The study was done in the city of Baltimore, and it is a sound study. And it concludes some things that are perhaps finding. One is that kindergarten leads to early cognitive effects as measured on standardized tests more noticeably for black children than for white children. Kindergarten leads to fewer absences in the first grade. More kindergarten does not affect a child's deportment, their own expectations for their performance, or their parents' expectations for the child's performance or teacher judgments of personal maturity.

The study shows that kindergarten's effect is in education rather than in socialization for schooling.

More research is needed, the authors conclude, because their study was restricted to one school district. The authors suspect that there might be a progressive benefit to minority children as they progress through the school system based on their kindergarten experience. They also believe that it might be that the positive difference in marks received, that is, grades, has more lasting effect than gains on standardized achievement.

Consequently, more research is needed.

Now, this was a small research study. I think it was a good and sound study. And the question comes up how was it supported? Well, it was supported by a private foundation, not by the Department of Education. And in fact, when we talked with the authors about their funds, they said that very early they learned that there would be no support for this type of work from the Department of Education and that they would have to go elsewhere.

I have a lot of statistics in the paper about the proportion of the Federal expenditure for education that goes to educational research. I find it hard to visualize them so I brought in a graphic, and if you will consider each of these cards to be $100 million, this stack is what, according to the GAO report just issued, we spend for Defense R&D, and this card is what we spend for educational research.

Now, I have no way to evaluate the appropriateness or the benefits of this expenditure, but we can be fairly specific about this $100 million. That is it does not encourage young scholars to pursue careers in educational research, particularly minority scholars. Our ability to conduct studies has been depleted as reported by the GAO. And we have an overall decline of Federal support for educational research of about 70 percent since 1972. Investing in only one card in education research is not going to allow us to know how to explain math scores and how to become fully competitive, which I am sure is what the Congress is interested in achieving.

Most recently, in the area of field initiated research, the Department of Education has an amount of $500,000, and that will permit the study, the award of 10 grants. There are already 220 applicants for those 10 grants, and obviously we are going to have more people waiting to do research than we are doing research.

PREPARED STATEMENT

Finally, the administration's 1989 budget request for OERI does not fully address the need for a vastly improved and enlarged education research effort, and in fact, it is not so much a step in the right direction as a slight lean in the right direction, but we think that it merits the support of Congress and that it is in the right direction, and we urge you to support and to fund the request that the administration has made.

Thank you.

[The statement follows:]

STATEMENT OF GERALD SROUFE

Good morning. My name is Gerald Sroufe. I am the Director of the Government and Professional Liaison Program of the American Educational Research Association. AERA is the professional association of the 14,000 men and women in the US, and abroad, who are vitally interested in the conduct of education research.

We appreciate this opportunity to testify before the Senate Appropriations Subcommittee on Education and Labor. I wish to use this time to challenge members of the Committee to adopt a somewhat different perspective about four aspects of education research: (1) statistics are not research; (2) "more research is needed;" (3) federal funding of education research is woefully inadequate; and (4) the budget proposed by the Administration for education research in 1989 merits the support of Congress.

1. Congress has been bold in the provision of a new structure and increased resources for gathering education statistics. Clearly education policy makers at all levels of government need accurate data on the education accomplishments of our children. The provisions of the Hawkins-Stafford Act will provide this information.

Statistical information is only the beginning of the process of developing data necessary for sound policy making, however. The information gained by the National Assessment of Education Progress, for example, will highlight both our educational successes and areas where more work is required. However, NAEP will not provide answers to the core policy questions: what effects are associated with alternative policies? To gain this information one must seek explanation and understanding. Explanation is what research seeks to provide.

For example, Congress is interested in preschool education as a vehicle for improving education across the board and, especially, for the disadvantaged. One reform that is instructive in the formulation of policy in this area is the growth of kindergarten programs within the states. It is relatively easy to gather statistics regarding the number of children in kindergarten and to compare this data on a state by state basis. It is much more helpful, however, if one can make dependable statements about the effect of kindergarten programs on the children of greatest concern--the disadvantaged.

CONGRESS IS CORRECT IN INSISTING ON MORE AND BETTER INFORMATION ABOUT THE PERFORMANCE AND CAPABILITY OF OUR EDUCATION SYSTEM. IT SHOULD ALSO INSIST THAT ADEQUATE RESOURCES BE AVAILABLE TO INTERPRET THE INFORMATION AND TO PROPOSE AND TEST ALTERNATIVE INSTRUCTIONAL AND ORGANIZATIONAL STRATEGIES DESIGNED TO IMPROVE THE RESULTS OF OUR CONSIDERABLE EXPENDITURES FOR EDUCATION. IF CONGRESS ACCEPTS RESPONSIBILITY FOR ADEQUATE INTERPRETATION AND EXPLANATION OF EDUCATION STATISTICS IT WILL NECESSARILY HAVE TO LOOK TO THE RESOURCES AVAILABLE FOR EDUCATION RESEARCH.

2. "More research is needed" is an expression that has become an anathema to some policy makers. Too frequently it is an indication that the study was ill considered and inconclusive. But in sound and serious research it is often the only reasonable outcome and is indicative of a successful study. More research can only be justified if the research already undertaken has been shown to be productive; if resolution of initial questions has raised even more important ones, or if the findings are of such potential that the expense of testing them further and more completely is justified.

For example, researchers at Johns Hopkins University have investigated the question of the impact of kindergarten on children's performance in the first grade. They were interested in knowing whether the impact of kindergarten would be in development of social skills or conceptual skills, and whether the impact was the same for all children or varied systematically according to race, sex, or income level. Their findings, based on a large sample of students in the Baltimore schools, included several points that will be of interest to the Committee and the education community: (1) kindergarten leads to early cognitive effects as measured on the California Achievement Test (CAT), more noticeably for blacks than whites; (2) more kindergarten leads to fewer absences in the first grade, (3) more kindergarten does not affect children's deportment, expectations for their performance, parents expectations of their children's performance; or teacher judgements of personal maturity.

These findings are important in the current discussion about the nature and amount of preschool education and its likely effect on the achievement and persistence of students. More research is needed because the study was restricted to one school district; because the authors suspect that there may be a progressive benefit to minority children through kindergarten experience as they proceed through the system; and because important questions about the relationship of school marks to later success were raised: apparently positive differences in marks received are more lasting than gains on standardized achievement tests such as the CAT.

This was a good research study: it considered an important question in a serious fashion. How was it supported? In part by a private foundation and in part by NICHD. It received no direct support from the Department of Education. Indeed, the authors report that early in their investigation they realized they would receive little financial help from the Department. Consequently, there research in conduct of the Beginning School Study has struggled to secure funds from a variety of agencies and foundations other than the Department of Education, even though their research is pertinent to a central education policy issue.

3. Less than one-half of one percent of the federal expenditure in education is allocated to education research. Is this enough? Industry believes that about three percent of the operating budget should be provided to research and development. In the public sector, the Defense department spends about this amount on research and development. Most of the budget of the National Institute of Health is invested in research. In comparative terms, too small a portion of the federal expenditures in education is allocated to research.

In absolute dollars, our country provides about 36 billion dollars for research and development associated with defense, 7 billion on health and human services related research, but only 126.1 million for education research (including statistics, evaluation, technical assistance, and research). According to a recent GAO report (May 1988, R & D Funding: The Department of Education in Perspective), less than two-tenths of one percent of federal research dollars are invested in education.

In terms of improving our capacity to conduct sound research the federal contribution is inadequate. There is no encouragement for young scholars to pursue careers in education research, particularly minority scholars; our ability to conduct studies, as depicted in the GAO study (November,

1987) Education Information: Changes in Funds Have Affected Production and Quality),grants and contracts awarded decreased 65 percent from 1980 to 1985; the number of evaluation studies decreased 79 percent in this same period. Overall, federal support for education research has decreased 70 percent in constant dollars from the 1970 level.

Finally, while our research centers are doing outstanding work, we are not providing opportunities for field-initiated research--studies conceived and conducted by individuals. About 1300 grants per year are provided by the National Science Foundation to individuals and groups to conduct independent research. The Office of Educational Research and Improvement (OERI), the major research agency of the Department of Education, made only 10 grants for field-initiated research in FY 1988. Field initiated research sponsored by NSF amounted to $1.5 billion; in OERI only $500,000 was invested in field-initiated research.

4. The Administration's 1989 budget request for OERI does not address the clear need for a vastly improved and enlarged education research effort. It does provide funds for additional research centers and for support of existing centers; it does provide a modest increase for field initiated research. It does not represent so much a step in the right direction as it does a slight inclination. Nonetheless, we urge Congress to provide, as a minimum, the funds requested by the Administration to further the important work of OERI in the conduct of education research through the centers and through field-initiated research.

Thank you for your time and attention. I will be pleased to answer any questions about this testimony or to provided additional information to the Subcommittee.

Senator **Burdick**. According to the notes I have here, the 1989 administration request is for $84 million, and your recommendation of the citizens is for $84 million, is that right?

Dr. **Sroufe**. Yes.

Senator **Burdick**. Actually, an increase of 16 percent, or $16 million over 1988.

Dr. **Sroufe**. I think the increase is a bit misleading because a good deal of that money is in the statistics program, and in fact, it is not new money; it is money transferred from ongoing programs, but it is an increase. It is one of the few times that an increase has been requested.

Senator **Burdick**. Thank you.

Dr. **Sroufe**. Thank you.

STATEMENT OF FRANCIS LAWRENCE, ASSOCIATION OF AMERICAN UNIVERSITIES, AND NATIONAL ASSOCIATION OF STATE UNIVERSITIES AND LAND-GRANT COLLEGES

Senator **Burdick**. Our next witness is Francis Lawrence, Association of American Universities and National Association of State Universities and Land-Grant Colleges.

Welcome to the committee, Mr. Lawrence.

Mr. **Lawrence**. Mr. Chairman and members of the subcommittee, thank you for giving me this opportunity.

I am here to offer you a slightly different and perhaps more personal perspective on graduate education. I represent the four national organizations concerned with graduate education, and I am provost and graduate dean of Tulane University, but I am also a former government fellowship holder.

I am still very grateful to Uncle Sam for the NDEA title IV which supported me while I earned my Ph.D. from 1959 to 1962. But what was possible for me in 1959, as a proud part of our national defense effort in education, is no longer conceivable for most graduate students today. Today, graduate education seems to be regarded as a benefit primarily to the individual, and government support for graduate and professional students is granted mostly in the form of loans.

Tulane's current graduate students earn their $3,000 to $9,000 stipends by teaching two to four classes. They moonlight as well to support themselves and their families. Loans are a realistic alternative for professional students, but Ph.D. students do not have a definite limited term of training and cannot rely on future income that will justify and repay a large debt.

This is not just a sob story about our overworked graduate students who must take 6 to 10 years to earn their degrees or drop out in discouragement along the way. Our bright undergraduates have figured out the odds for themselves. Without adequate funding for service-free fellowships, graduate school has become a terrifying gauntlet that fewer and fewer American students choose to run.

As a result, in order to sustain our programs of undergraduate education and graduate research, we now accept a growing number of well qualified foreign students, particularly in science and engineering. More than 50 percent of U.S. doctoral degrees in engineering are granted to foreign students, but only one-third of foreign Ph.D.s stay in this country. The dearth of American Ph.D.s has serious implications both for our competitiveness in research and for undergraduate education. By the midnineties we foresee growing college enrollments and increased faculty vacancies occurring simultaneously.

We need to persuade our talented minority students to get Ph.D.'s, to meet projected demands for faculty, because we must have minority faculty in order to encourage young minority people to get college degrees. They will soon become 30 percent of our 18 to 24 year olds and will increase to nearly 40 percent by the year 2025.

Not only do we need educated citizens to remain competitive in a technologically sophisticated world market, but as high paying manufacturing jobs for noncollege graduates give way to low paying retail and service jobs, a college education is increasingly important to the ability to support a family without public assistance.

My point is that graduate education is not an elitist indulgence that concerns only graduate deans and universities; it is an urgent national problem that deserves consideration as part of our national defense and our national pride.

Thank you.

Senator BURDICK. Thank you very much.

STATEMENT OF ALLAN W. OSTAR, PRESIDENT, AMERICAN ASSOCIATION OF STATE COLLEGES AND UNIVERSITIES, ON BEHALF OF THE NATIONAL PELL GRANT COALITION

Senator BURDICK. The next witness will be Allan Ostar, president, American Association of State Colleges and Universities, National Pell Grant Coalition.

Mr. OSTAR. Good morning, Senator. My name is Allan Ostar, and I am here representing the National Pell Grant Coalition. This is a group which my association, the American Association of State Colleges and Universities, is a charter member.

The Pell Grant Coalition represents 33 national education, labor, student, and civil rights organizations which are united in supporting Pell grants as the most important national embodiment of our society's commitment to accessible higher education.

Over 3 million students now receive Pell grants. Most are very low income. About one-half have family incomes below $7,500. About one-third are minorities, and most are the first members of their families to go to college.

The program's continued strength after years of attack by the administration is in large measure due to the work of this subcommittee and its counterpart in the other body. For that I extend special thanks to members of the subcommittee on both sides of the aisle.

This subcommittees work on behalf of Pell grants touches people's lives in concrete and constructive ways. News reports this year indicate minority applications to college may be starting to move up again slightly. We believe this may represent a small sign of renewed confidence on the part of minority students that college is a realizable, affordable goal, and we further believe that this is based, at least in part, on the fact that next fall will mark the first Pell grant benefit increase in 3 years, and that 1988 has also seen the end of 7 years of administration attempts to eviscerate the program.

Despite these signs of renewal, however, the Pell Grant program faces great challenges. In 1979, almost one-half of the average cost of college attendance was covered by the maximum Pell award. In sharp contrast, as we begin the 1988–89 year, the maximum grant of $2,200 will provide only 29 percent of the average college cost.

The administration has proposed a $100 increase in the maximum grant for fiscal year 1989, welcome news after years of proposed cutbacks, and made more gratifying because the budget assumes implementation of the legislative mandate opening Pell eligibility to the lowest income students attending college less than half time.

But the fact is that an increase of only $100 is not sufficient to meet student needs or even keep pace with rising costs. Indeed, the proposed $2,300 grant would cover less than 29 percent of the average college cost we anticipate for 1989–90, the lowest proportion ever covered in the history of the program.

Instead of accepting this result, our coalition urges you to set the award ceiling at $2,400, an amount which at least would keep the shortfall between benefit levels and college costs from growing wider.

PREPARED STATEMENT

Mr. Chairman, in America today a college education is becoming the single dividing line between a productive, satisfying career and a life on the economic margin. Under these circumstances, it is essential that we vigorously support programs like Pell grants which make advanced education economically feasible for all.

Thank you, sir.

[The statement follows:]

STATEMENT OF ALLAN W. OSTAR

Thank you for extending to me this opportunity to testify on behalf of the National Pell Grant Coalition, a group of which my association-- the American Association of State Colleges and Universities-- is a charter member. The Pell Grant Coalition represents 33 national education, labor, student and civil rights organizations, which are united in supporting Pell Grants as the most important national embodiment of our society's commitment to accessible higher education.

Over three million students now receive Pell Grants. Most are very low income-- about half have family incomes below $7,500-- about one-third are minorities, and most are the first generation of their family in college. The program's continuing strength, after years of attack by the Administration, is in large measure due to the work of this subcommittee and its counterpart in the other body. For that I extend special thanks to you, Mr. Chairman, and to the ranking minority member, Senator Weicker.

This committee's work on behalf of Pell Grants touches peoples' lives in a concrete and constructive way. News reports this year indicate minority applications to college may be starting to move up again. We believe this may represent a small sign of renewed confidence on the part of minority students that college is a realizable, affordable goal. And we further believe that this is based, at least in part, on the fact that next fall will mark the first Pell Grant benefit increase in three years, and that 1988 has also seen the end of seven years of Administration attempts to eviscerate the program.

Despite these signs of renewal, however, the Pell Grant program faces great challenges. In 1979, almost half of the average cost of college attendance was covered by the maximum Pell award. In sharp contrast, as we begin the 1988-89 academic year, the maximum grant of $2,200 will provide only 29% of that average college cost.

The Administration has proposed a $100 rise in the maximum grant for fiscal 1989-- welcome news after years of proposed cutbacks, and made more gratifying because the budget assumes implementation of the legislative mandate opening Pell eligibility to the lowest-income students attending college less than half-time. But the fact is that an increase of only $100 is not sufficient to meet student needs or even keep pace with rising costs. Indeed, the proposed $2,300 grant would cover less than 29% of the average college costs we anticipate for 1989-90, the lowest proportion ever covered in the history of the program.

Instead of accepting this result, our Coalition urges you to set the award ceiling at $2,400, an amount which, at least, would keep the shortfall between benefit levels and college costs from growing wider.

Mr. Chairman, in America today a college education is becoming the single dividing line between a productive, satisfying career and a life on the economic margin. Under these circumstances, it is essential that we vigorously support programs like Pell Grants which make advanced education economically feasible for all. Thank you.

Senator **Burdick**. Thank you.

I noticed that the 1989 President's request is for $511 million, higher than last year by $600,000 or $700,000.

Is that adequate?

Mr. **Ostar**. No, sir; it is not adequate. We believe within the administration's request for $750 million increase that a maximum grant of $2,400 can be accommodated. But we do believe that a $2,400 maximum Pell is absolutely critical if we are to provide opportunity for those who need it the most.

Senator **Burdick**. Maybe you can straighten it out. I have conflicting information.

Is it fair to say that your request is for the Pell grant to have a maximum grant of $2,400?

Mr. **Ostar**. That is right.

Senator **Burdick**. Thank you.

I turn the gavel to you, sir.

STATEMENT OF MARY J. PRESTON, LEGISLATIVE DIRECTOR, U.S. STUDENT ASSOCIATION

Senator **Hatfield** [presiding]. I would like to invite Mary J. Preston, legislative director, U.S. Student Association.

Good morning.

Your entire statement will be placed in the record, and you may proceed to summarize or highlight as you may wish.

Ms. **Preston**. Thank you.

I am Mary Preston, and I am the legislative director of the U.S. Student Association. It is a pleasure to appear before you on behalf of the students whom I represent.

As you know, we are a national membership organization of college and university students, and we seek to expand and improve educational opportunity for all individuals in our national.

I will not repeat the testimony of my previous colleague, Dr. Ostar, but I will strongly endorse his testimony and urge the committee to appropriate a $2,400 maximum Pell grant. Without this, we will be losing ground, and as you know, Pell is the cornerstone of the Federal financial aid programs.

I would like to speak for a minute about the TRIO programs, special programs for disadvantaged students. They are the most effective Federal retention programs. They serve low income, first generation to attend college and physically challenged students, and they reach disadvantaged high school students as well as adults by providing information, counseling, tutoring and role models needed to get at-risk and low income individuals interested in and prepared for and able to succeed in college.

As recent hearings on the guaranteed student loan default issue noted, a major contributing factor encouraging default on a student loan is lack of educational success. TRIO does what no student aid program alone can do, and that is to help those most at risk of educational failure to achieve success in school.

It is also not enough for us to put up "Just Say No" posters in school halls and streets in burned out neighborhoods and expect kids to avoid drugs when the only concrete economic success stories they see are individuals involved in drug pedaling.

We need to present positive alternatives and real opportunities for people in these communities, or the most aggressive "Say No" campaign will be inadequate.

TRIO provides the role models and counseling which in a real sense represent these opportunities.

We have never reached more than around 10 percent of individuals in our Nation who are eligible for TRIO funding. In recent times we have been cultivating a whole new bumper crop of new poor, and more individuals will continue to be eligible for those programs. To begin to keep up with the need for TRIO services, we must fund TRIO at $250 million this year. While this will not go near meeting the need, it will bring us back up near 1980 service levels.

In the final year of this administration, it would be a great victory to get us back to where we were 8 years ago in this area. Perhaps then in the new administration of whatever party we can move toward meaningful increases in these highly successful and cost-effective programs.

I would also like to note a new program under the TRIO programs which is the Ronald E. McNair scholarships. I am sure my colleagues at the National Council of Educational Opportunity Associations will discuss these.

This program is the first education department program to be named after a black male. That at first may seem trivial or gratuitous, but it becomes less so when we realize the crisis situation which we face. One-half as many black men earned Ph.D.'s in 1986 as did in 1976. When we face a situation which is this acute, I think you will agree that the McNair scholarships are important in two ways: No. 1 and foremost, for the concrete money and the people it will help, and No. 2, for the symbolic commitment which the Federal Government will be making to the educational success of this group.

PREPARED STATEMENT

I would also like to speak strongly for the campus based programs. They are important programs, and we urge increases to keep pace with inflation and college costs. We support the funding for graduate scholarships and fellowships, for minority assistance in areas of national need, et cetera, and we urge you to reject selling out the national direct student loan in favor of the income contingent loan program, which I think you will probably agree.

Senator HATFIELD. Thank you very much. Your time has expired.

[The statement follows:]

STATEMENT OF MARY J. PRESTON

Mr. Chairman and members of the Subcommittee, I am Mary J. Preston and I am the Legislative Director at the United States Student Association. It is a pleasure to appear before you to present USSA's recommendations for higher education appropriations in fiscal year 1989. Before I begin I would like to note that I am the Legislative Co-Chair of the National Coalition for Women and Girls in Education, which is presenting written testimony to you in regard to the Women's Educational Equity Act. USSA endorses this testimony, I ask that it is inserted into the record along with my written remarks.

The United States Student Association is a national membership organization representing students attending diverse colleges and universities from around the country. Our primary goals are to increase access to postsecondary education, and to improve educational opportunity for all individuals in our nation.

USSA recommends the following levels of funding for postsecondary education programs. We thank you for your consideration of our recommendations.

PELL GRANTS

Pell Grants are the cornerstone of the federal financial aid programs, providing about three million students with grant assistance. An estimated 78% of Pell Grant appropriations go to students with adjusted incomes of $15,000/year or less. Nearly one half of Pell funds assist those with family incomes of $7,500/year or less. Fewer than 4% of the funds benefit students from families earning over $25,000/year.

USSA strongly supports an increase in the maximum Pell Grant to $2,400 in FY 89. The President has requested a $2,300 maximum grant, but this would fail to keep pace with college costs and would actually cover less of the costs than this year's maximum of $2,200. The FY 88 level will cover 29% of average college costs this year. If the maximum grant is raised to only $2,300 in FY 89, Pell will fall for the first time below 29% of total costs.

The value of the Pell Grant has declined 30% since 1980, when we take into account inflation and college cost increases. An increase of $200 over the FY 88 appropriations level will merely keep the value of Pell from declining further. It is the least we should do to assist the most needy students to attain a college education. We recommend an appropriation sufficient to cover the $2,400 grant.

TRIO PROGRAMS

TRIO Programs, or Special Programs for Disadvantaged Students, are the most effective federal retention programs. Serving low-income, first generation to attend college, and physically challenged students, TRIO programs reach disadvantaged high-school aged students as well as adults by providing the information, counselling, tutoring, and role models needed to get individuals interested in, prepared for, and able to apply to college. Student support services then assist those same students to stay in school by providing many of these same services.

A recently authorized program, Ronald E. McNair post-baccalaureate achievement scholarships, has not yet been funded. We recommend an appropriation of $2 million to assist more low-income students to receive doctorate degrees.

As recent hearings on the Guaranteed Student Loan default issue note, a major contributing factor encouraging default on a loan is lack of educational success. TRIO programs do what no other federal aid programs do: help those most at risk of educational failure to achieve success in school.

The number of students served under TRIO has declined since 1980 as federal appropriations have failed to keep pace with programs costs and inflation. TRIO must be funded at $249.7 million in FY 89 to restore services to 1980 levels. $249.7 million is a very reasonable request to assist upwards of 529,500 students to enroll and succeed in postsecondary education, and USSA strongly encourages the Congress to invest this amount.

CAMPUS-BASED PROGRAMS

College Work Study, Supplemental Educational Opportunity Grants, and State Student Incentive Grants give financial aid administrators the flexibility to assess individual need and to award relatively small amounts of aid to students needing additional financial assistance to enroll or remain in school. USSA supports increases in these important programs to keep pace with inflation and college costs.

TITLE IX

USSA supports funding for graduate assistance, particularly to encourage minority participation in graduate education (HEA IX-A). Racial minorities are grossly underrepresented at all levels of postsecondary education except for two year and vocational colleges, and the situation is not currently improving. Enrollment of Blacks in graduate school peaked in academic year 1976-77. If we fail to promote Blacks' and other racial minorities' participation in higher education at the graduate level, we will continue to have extremely poor representation of Black and other minority professors. USSA recommends an appropriation of $10 million to fund this important initiative in its second year.

USSA encourages the Congress to reject the wholesale cuts requested in the Patricia Roberts Harris fellowships and Graduate assistance in areas of national need (IX-D). Congress has recognized the need for increased support for graduate education even in these difficult budget years, and we support continuation of this important federal commitment.

FEDERAL LOAN PROGRAMS

USSA supports the Perkins (formerly the National Direct Student Loan) program as a supplement to need-based grant programs, and we recommend the continuation of capital contributions into the program. Like the campus-based grant programs (SSIG, College Work Study, and SEOG), Perkins loans provide for flexibility on the part of the financial aid administrator to assess individual need and to deliver money to those students with exceptional need.

USSA opposes the Administration's requested increase in the Income Contingent Loan pilot program. What we find most unattractive about the Income Contingent Loan is not its income contingency, but the fact that interest accrues during the period of enrollment, and that interest rates are not fixed. Because of this, borrowers with modest incomes pay much more than those who immediately enter high-paying fields. In fact, some individuals might continue to pay interest for many years without ever reducing the actual principal on the loan. We oppose any increase in this program particularly because it would sap the already inadequate resources going toward other need-based student financial assistance programs.

Mr. Chairman, I will close by acknowledging that resources are scarce in FY 89, and that all worthy programs may not be funded in their entirety this year. Education should always be, however, regarded as an investment, not merely an expenditure. Adequate investment in our nation's children, students, and schools will do for our competitiveness what no high-technology research will. It also saves us countless future dollars spent on welfare, crime prevention, jails, and subsidies for the undereducated and unemployable. We at USSA ask you and your committee to keep this in mind as you grapple with federal appropriations for fiscal year 1989. Thank you for the opportunity to present the views of the United States Student Association to this committee.

STATEMENT OF G.W. MINGO, PH.D., DIRECTOR, STUDENT SUPPORT SERVICES AND UPWARD BOUND, UNIVERSITY OF FLORIDA, ON BEHALF OF NATIONAL COUNCIL OF EDUCATIONAL OPPORTUNITY ASSOCIATIONS

Senator HATFIELD. I would like to invite now Dr. G.W. Mingo, student support services-Upward Bound, University of Florida, National Council of Educational Opportunity Associations.

I would like to express to you, sir, that the chairman of the subcommittee, Senator Chiles of Florida, had hoped to be able to be here to present you, to introduce you and to welcome you. I do so on his behalf in that he has been unavoidably detained in another assignment.

Dr. MINGO. I thank you for the opportunity to testify before the subcommittee today. I direct a Student Support Services Program and Upward Bound Program at the University of Florida, and I have done that since 1974. I am testifying today on behalf of the National Council of Educational Opportunity Associations.

Our TRIO programs address the problems of minority access to higher education. We are very supportive, as was indicated by the previous speaker, of the type of activities that we provide for them, and one of them is in the manner of modeling, being a positive role model for the students.

Among the higher education programs your subcommittee has put the highest priority on Pell grants, realizing that without sufficient resources, low-income students will simply not be able to attend college. We in the TRIO program applaud this effort and emphasis. But this subcommittee has also recognized that a series of nonfinancial barriers are similarly important in limiting students' access and retention. Lack of peer and familial support, lack of information about opportunities available, and lack of appropriate academic preparation can prevent minorities and other low-income students from graduating from college.

One can turn to a number of successful graduates of my program and gain an understanding for some of the barriers that they can overcome. Take, for example, Cleveland Franklin; a student of my 1980 Upward Bound Program. Cleveland came from Hawthorn, FL, a small town in Alachua County of approximately 1,500 residents. Cleve is the first member of his family to graduate from college, and without his experiences in the Upward Bound Program, he probably would not have had the career options that were opened to him throughout summer programs.

Cleve decided to become a pharmacist. He received a pharmacy degree from Florida A&M, and after working for some time in Jacksonville and Tampa, he has returned to this community of 1,500 people, and he is now the only pharmacist in that city. Cleve has inspired other individuals of his community to go on to college and pursue degrees in science.

Tyrone Hutchinson, a 1983 graduate of our Upward Bound Program, recently graduated from Tuskegee University in chemistry, and he will enter medical school this fall.

We are also troubled by the recent report of low mathematics skills released by the National Assessment of Educational Progress, and Senator Chiles also commented on this report, that it is tragic. We offer at our student support services program in Florida, for example, tutoring in mathematics and sciences to assist these underprepared students in grappling with the deficiencies in their preparation.

PREPARED STATEMENT

Genette Johnson, a 1978 graduate of our program in Florida, came to us with inadequate preparation in the mathematics and the sciences, and today she is a medical doctor, having received a chemistry degree from our institution, a pharmacy degree, and a medical doctor's degree. She is presently doing her residency in Jacksonville, FL.

[The statement follows:]

STATEMENT OF G.W. MINGO

Mr. Chairman, Members of the Subcommittee. I very much appreciate the opportunity to testify before the Subcommittee today. I particularly appreciate the opportunity to thank Senator Chiles and Senator Hollings for their strong advocacy for the TRIO programs within the Congress in Fiscal 1988. The increase provided the TRIO programs, despite budget constraints, gives remarkable evidence of the Congress' concern regarding declining enrollments of low-income and minority students in higher education.

My name is G.W. Mingo and I have directed the Student Support Services and the Upward Bound programs at the University of Florida since 1974. I am testifying today on behalf of the National Council of Educational Opportunity Associations. Our Student Support Services project in Gainesville annually provides tutoring and counseling to 150 minority undergraduates at the University. Our Upward Bound program enrolls 80 low-income high school students from Alachua County.

As you know, over the past several years, American college presidents have begun to confront the demographic changes which are occurring. The overall college population will continue to decline between now and the year 2000, and that decline will result mainly from the shrinking white population. Meanwhile, the black, American Indian and Hispanic population is younger than the white population and growing at a faster pace. Thus, in contrast to whites, the proportion of minority college-age persons will rise. By the year 2,000, minorities will indeed make up a third of the nation.

As Reginald Wilson and Manuel Justiz commented in a recent article in Educational Record, the changing demographics are an explosive issue for higher education because colleges and universities have not brought minorities onto their campuses in numbers comparable to their representation in society."

The attached table gives clear evidence that college participation rates for minority youth have been declining in the 1980's. Black high school graduates have been enrolling in college at a substantially lower rate. Between 1971 and 1976, the percentage of black high school graduates attending college rose from 18.2% to 22.6%. However, by 1985, black enrollments had declined to 19.8% and they continue to decline. College enrollment rates for Hispanics suffered similar losses during this time.

While Hispanics have made considerable gains in the number of degrees earned, they continue to be one of the most underrepresented populations in higher education. As of academic year 1985-86, Hispanics represented 8.2% of the 18-24 year old population, but only 4.3 % of college enrollment and received only 2.7% of baccalaureate degrees conferred.

Blacks were the only ethnic group to experience declines in the numbers of degrees awarded in the 1980's. Blacks made up 13.7% of the 18-24 year old population, but only 9.5% of college enrollments. Moreover, blacks received only 5.9% of baccalaureate degrees awarded.

How Do TRIO Programs Address the Problems of Minority Access to Higher Education?

Among higher education programs, your Subcommittee has put the highest priority on Pell grants realizing that without sufficient resources, low-income students will simply be unable to attend college. We in the TRIO programs applaud this emphasis. But this Subcommittee has also recognized that a series of non-financial barriers are similarly important in limiting student access and retention. Lack of peer and familial support, lack of information about opportunities available, and lack of appropriate academic preparation can all prevent minority and other low-income students from graduating from college.

One can turn to any number of the successful graduates of my programs and gain an understanding of some of these barriers--and how they can be overcome. Take for example, Cleveland Franklin, a 1980 graduate of Florida's Upward Bound project. Cleveland came from Hawthorne which, as you may know, is a town of about 1,500 near Gainesville. Cleveland was the first in his family to attend college and, prior to entering Upward Bound, had a limited understanding of all of the career options that were open to him. However, through participation in the Upward Bound summer programs, Cleveland decided on a career in pharmacy.

He received his degree at Florida A&M, and after working for some time in Jacksonvile and Tampa, returned to Hawthorne as the town's only pharmacist. Cleveland has also inspired a number of other black youth from Hawthorne to attend college and to pursue careers in the sciences. Tyrone Hutchinson, a 1983 graduate of the University's Upward Bound program recently graduated from Tuskegee as a Chemistry major and will enter medical school in the fall.

How do TRIO Programs Address the Problems of Minority Underpreparedness?

All of us were troubled by the recent report on mathematics skills released by the National Assessment of Educational Progress. As Senator Chiles commented on the report, it is tragic. There is no way young people with these skills are going to meet their full potential. It is equally disturbing that skills as essential as mathematics and science are disproportionately distributed on the basis of race. While eight percent of white students are performing at the highest levels of mathematics achievement, less than one-third of one percent of black students are performing at this level, and the number of Hispanic students performing at this level is so small as to be insignificant.

The 650 Student Support Services programs are one of the few vehicles available to assist low-income and other first-generation students in making up the deficiencies in their earlier preparation and pursuing careers of their choice. Our Student Support Services program at Florida, for example, offers tutoring in mathematics and the sciences to assist underprepared students in grappling with deficiencies in their preparation.

It also provides academic advising to assure that students with insufficient preparation do not attempt unrealistic course loads--course loads that might doom them to failure not based on aptitude but on preparation. Finally, our program works closely with other academic units to assure that students who do need remediation receive it. All of these services are provided at a per student cost of $590.

Genette Johnson is a 1978 graduate of that program who enrolled at Florida with inadequate preparation in mathematics and the sciences. In fact, her test scores were so low that she was admitted to the University on a conditional basis. However, through tutoring, counseling and remedial coursework, Genette graduated with a degree in both chemistry and pharmacy. She later completed her medical degree at the University of Florida and is presently a resident in Jacksonville.

TRIO is able to assist minority and other low-income students in beating the odds because it provides them the support they need to access an often complicated financial aid system and to overcome the non-financial barriers which limit their ability to achieve the upward mobility to which they aspire.

Recommendations Regarding Fiscal 1989 Funding

The NCEOA is recommending a funding level for TRIO programs of 250 million in fiscal 1989. This would allow the programs to serve the same number of students that were served in Fiscal 1980 and to fund the Ronald E. McNair Post-Baccalaureate Achievement Program at its authorized level. In 1980, 527,000 students were served by TRIO programs. In fiscal 1988, despite your attempts to restore funding for TRIO in fiscal 1988, only 456,000 students will be enrolled in four TRIO programs: Educational Opportunity Centers, Student Support Services, Talent Search and Upward Bound.

Other Concerns of the TRIO Community

The NCEOA shares your concern about the Administration's apparent unwillingness to fund the Ronald E. McNair Post-Baccalaureate Achievement Program which was named after Dr. McNair, the black Astronaut killed in the Challenger disaster. Your report accompanying the Fiscal 1988 Continuing Resolution made clear Congress' intent that this program be funded. This apparent disregard of the will of Congress is troubling. Equally troubling is a refusal by the Department of Education to acknowledge that unless the number of doctoral recipients from disadvantaged backgrounds is increased, it is very likely, according to the National Academy of Sciences, that the total number of doctorates awarded will decline. The Research Council specifically recommends programs like McNair to address this critical problem. Yet despite this fact, and despite the fact that their failure to fund the only education program named to honor a black male offends many in the black community, the Department has adamantly refused to implement this program.

A final concern of the NCEOA is the unwillingness of the Department of Education to expand the availability of Educational Opportunity Center and Talent Search services. Given the complexity of the student financial aid system--and the lack of awareness in low-income communities regarding aid available from federal, state and private sources--a deliberate attempt to increase awareness among these populations regarding educational opportunities is necessary if we are to reverse the enrollment declines discussed above. Educational Opportunity Centers and Talent Search programs provide a very cost effective mechanism for achieving this goal. Yet the Administration has chosen not to expand these vital services despite the fact that Congress made monies available for this purpose.

I appreciate the opportunity to testify before you today and would be pleased to answer any questions you might have.

Table 1
High School Completion (1) and College Entrance Rates for Population 18–24 Years Old by Race/Ethnicity: United States, Selected Years
(Number in Thousands)

	1971	1976	1981	1985
Total:				
Total population 18-24-yr.-olds	23,668	26,919	28,965	27,122
Number completing high school	18,691	21,677	23,343	22,349
Number enrolled in college	6,210	7,181	7,575	7,537
H.S. graduates as a percentage of total	79.0%	80.5%	80.6%	82.4%
College entrants as a percentage of 18-24-yr.-old H.S. graduates	33.2%	33.1%	32.5%	33.7%
College entrants as a percentage of 18-24-yr.-old population	25.2%	26.7%	26.2%	27.8%
White:				
Total population white 18-24-yr.-olds	20,533	23,119	24,486	22,632
Number completing high school	16,693	19,045	20,123	18,916
Number enrolled in college	5,594	6,276	6,549	6,500
H.S. graduates as a percentage of total	81.3%	82.4%	82.2%	83.6%
College entrants as a percentage of 18-24-yr.-old H.S. graduates	33.5%	33.0%	32.5%	34.4%
College entrants as a percentage of 18-24-yr.-old population	27.2%	27.1%	26.7%	28.7%
Percentage of the total 18-24-yr.-old population	86.6%	85.9%	84.5%	83.4%
Black:				
Total population Black 18-24-yr.-olds	2,866	3,315	3,778	3,716
Number completing high school	1,789	2,239	2,678	2,810
Number enrolled in college	522	749	750	734
H.S. graduates as a percentage of total	62.4%	67.5%	70.9%	75.6%
College entrants as a percentage of 18-24-yr.-old H.S. graduates	29.2%	33.5%	28.0%	26.1%
College entrants as a percentage of 18-24-yr.-old population	18.2%	22.6%	19.9%	19.8%
Percentage of the total 18-24-yr.-old population	12.1%	12.3%	13.4%	13.7%
Hispanic(2):				
Total population Hispanic 18-24-yr.-olds	1,338	1,551	2,052	2,221
Number completing high school	694	862	1,144	1,396
Number enrolled in college	179	309	342	375
H.S. graduate as a percentage of total	51.9%	55.6%	55.8%	62.9%
College entrants as a percentage of 18-24-yr.-old H.S. graduates	25.8%	35.8%	29.8%	26.9%
College entrants as a percentage of 18-24-yr.-old population	13:4%	19.9%	16.6%	16.9%
Percentage of the total 18-24-yr.-old population	5.6%	5.7%	7.1%	8.2%

NOTES: (1) Since these high school completion rates were calculated by adding the numbers of individuals in this age group enrolled in college as of October of that year and the number of high school graduates not enrolled in college, these rates include individuals who enrolled in college without receiving a high school diploma or a GED. Several states do not require entering junior college students to have a diploma or GED. Therefore, these high school completion rates will be slightly higher than figures that do not include this relatively small population.

(2) Hispanics may be of any race.

SOURCES: U.S. Department of Commerce, Bureau of the Census *Current Population Reports, Series P-20*, 247, 308, 373 and 408.

Senator HATFIELD. Thank you, Dr. Mingo. Your entire statement will be placed in the record, and we appreciate very much your coming here to testify.

Dr. MINGO. One thing, if I can just mention this, it is very important, we are requesting a $250 million increase—correction, funding level. This will be an increase over the previous year, and this will allow us to come up to our 1980 level.

Thank you very much for allowing me this opportunity to testify.

Senator HATFIELD. Thank you, Dr. Mingo.

STATEMENT OF JAMES RENICK, PH.D., ASSISTANT DEAN, GRADUATE SCHOOL, UNIVERSITY OF SOUTH FLORIDA, TAMPA, FL, ON BEHALF OF THE NATIONAL ALLIANCE FOR MINORITY GRADUATE PROFESSIONAL EDUCATION

Senator HATFIELD. I would like to invite now Dr. James Renick, assistant dean of the University of South Florida from Tampa, representing the National Alliance for Minority Graduate and Professional Education.

I would like to extend to you greetings on behalf of our chairman, Senator Lawton Chiles, Dr. Renick.

Dr. RENICK. Thank you, Mr. Chairman and members of the subcommittee. I am pleased to present testimony to you today in support of adequate funding for the Patricia Roberts Harris Graduate Fellowship Program.

This Patricia Roberts Harris Graduate Fellowship Program authorizes the Secretary of Education to award discretionary grants to institutions of higher education to assist minorities and women to undertake graduate and professional study in fields in which they have been traditionally underrepresented.

In 1985–86, the minority group representation in the program included blacks, 41 percent; Hispanics, 21 percent; Asian Americans, 11 percent; Native Americans, 6 percent; and white females, 21 percent. Overall, women comprised more than 50 percent of the 1,417 fellows awarded during academic year 1985–86.

It is very questionable whether these individuals would have pursued graduate study in the absence of this program. Students studying in the fields of engineering and physical and life sciences received over 50 percent of the fellowships awarded in 1985.

As you can see, Mr. Chairman, this program, while modest in scope of the entire education budget, represents a very significant contribution in terms of resources to continued opportunities for minority students and the institutions to train these students.

For Patricia Roberts Harris graduate fellowships for fiscal year 1989, the President has recommended $15,304,000, the same amount as the current 1988 funding level. This would support virtually the same number of fellowships, 900, as in the current year.

The Higher Education Reauthorization Act of 1986 modified the graduate professional opportunity program by redesigning it as the Patricia Roberts Harris fellowship. The program was significantly improved by increasing the level of each fellowship to $16,000 per year from the level of $8,400 per year.

This program improvement, however, created a significant gap in the education's ability to continue to fund the same amount of fellowships at the increased rate. The increased level of funding provided by Congress for the current fiscal year has allowed the department to fund the same amount of fellowships, but because of the increased stipend level, an increased appropriation is necessary for fiscal year 1989 to restore the number of fellowships to the pre-1987 levels.

It appears that if just the current level of funding were maintained, a slow but steady decline would occur in the number of new fellowships made available. A fiscal year 1989 appropriation of $22,500,000 would allow restoration of fellowships to the fiscal year 1986 level of 1,400 and provide the additional funding for each fellowship authorized by the Higher Education Act Amendments of 1986.

Mr. Chairman, we have listed below in chart form the current status of the program and our recommendations. Currently, in fiscal year 1988 there is a significant decrease in the number of fellowships being funded compared to previous levels. The recommendations that our organization makes will restore the number of fellowships to 1,400.

PREPARED STATEMENT

Thank you for the opportunity to present our views. We certainly look forward to working with you and your subcommittee to provide adequate resources for Patricia Roberts Harris fellowships.

Senator HATFIELD. Thank you very much, Dr. Renick. We appreciate your presence.

[The statement follows:]

STATEMENT OF JAMES RENICK

Mr. Chairman, and Members of the Subcommittee, I am pleased to present testimony to you today in support of adequate funding for the Patricia Roberts Harris Graduate Fellowship program.

The Patricia Roberts Harris Graduate Fellowship program (formerly known as the Graduate and Professional Opportunity Fellowship program) authorizes the Secretary of Education to award discretionary grants to institutions of higher education to assist minorities and women to undertake graduate and professional study in fields in which they have been traditionally under-represented. The Department allocates fellowships on a competitive basis to institutions with doctoral and professional degree programs in which there is a national need for highly trained individuals. The institutions, in turn, recruit individuals from under-represented groups and award fellowships to students who demonstrate financial need and who plan to pursue advanced degrees in approved academic areas.

In 1985-86, minority group representation in the program included: Blacks (41%), Hispanics (21%), Asian-Americans (11%), Native Americans (6%), and white females (21%). Women, overall, comprised more than 50 percent of the 1417 fellows supported during academic year 1985-86. It is very questionable whether these individuals would have pursued graduate study in the absence of this program. Students studying in the fields of engineering and the physical and life sciences received over 50 percent of the fellowships awarded in 1985. As you can see, Mr. Chairman, this program, while modest in the scope of the entire education budget, represents a very significant contribution in terms of resources to continue opportunities for minority students, and the institutions that train these students.

For Patricia Roberts Harris Graduate Fellowships for FY 1989 the President has recommended $15,304,000, the same amount as the current 1988 funding level. This would support virtually the same number of fellowships, 900, as in the current year.

The Higher Education Act Reauthorization of 1986 modified the Graduate Professional Opportunity Program by redesignating it as the Patricia Roberts Harris Fellowship Program. The Program was significantly improved by increasing the level of each fellowship to $16,000 per year from the level of $8,400 per year. This program improvement, however, created a significant gap in the Education Department's ability to continue to fund the same amount of fellowships at the increased rate. The increased level of funding provided by Congress for the current fiscal year has allowed the Department to fund the same amount of fellowships, but because of the increased stipend level an increased appropriation is necessary for FY'89 to restore the number of fellowships to the pre-1987 level. It appears that if just the current level of funding were maintained, a slow, but steady decline would occur in the number of new scholarships made available.

An FY'89 appropriation of $22,500,000 would allow restoration of fellowships to the FY'86 level of 1400, and provide the additional funding for each fellowship authorized by the Higher Education Act Amendments of 1986. Among these fellowships about 500 would be new, and would assure a continuation of progress for minorities seeking graduate education. It is likely, if funding for this program is not increased significantly that new fellowships would decline for several years, thus, severely undermining the intent of the program, and worse, eliminating a great number of opportunities for black and other minorities who wish to seek graduate professional education.

Mr. Chairman, we have listed below in chart form the current status of the program, and our recommendations.

Currently in FY'88, there is a significant decrease in the number of fellowships being funded compared to previous levels. The recommendations that our organization makes will restore the number of fellowships to 1400, the same number of fellowships that were funded in fiscal year 1986, before the Higher Education Act Amendments.

Thank you for the opportunity to present our views. We certainly look forward to working with your subcommittee to provide adequate resources for the Patricia Roberts Harris Graduate Fellowship program.

I am pleased to respond to any questions you have.

	FY'86	FY'87	FY'88	NAMGPE FY'89 proposed
Funding	$11,250,000	$11,750,000	$15,304,000	$22,500,000
# of Fellowships	1428	856	900	1400
$ Amount of Fellowship	$8,400	$16,000	$16,000	$16,000
o Student	$4,500	$10,000	$10,000	$10,000
o Institution	$3,900	$6,000	$6,000	$6,000

Senator **Hatfield**. At this time I would like to defer to Senator Grassley for the introduction of the next panel.

STATEMENT OF RALPH C. PORTER, PRESIDENT, NATIONAL COMMISSION FOR COOPERATIVE EDUCATION

Senator **Grassley**. Mr. Chairman, I appreciate very much the opportunity, even though I am not a member of this subcommittee, to have the opportunity to present to you the commission's president, Mr. Ralph Porter. I happen to be a trustee of the National Commission for Cooperative Education. It is a great pleasure for me to have worked with Mr. Porter on the reauthorization of the cooperative education title of the higher education bill during the 99th Congress.

Through the commission's role of advocacy and promotion, participation in cooperative education has grown from just 1,500 students in 1970 to the current level of 200,000. I hope the subcommittee will be most receptive to Mr. Porter's testimony which describes cooperative education's partnerships among students, employers and schools.

Mr. Chairman, because I am right next door participating in the Agricultural Subcommittee markup of appropriations, I regret that I am unable to remain for Mr. Porter's testimony.

I really appreciate the committee's allowing me this opportunity and Mr. Porter, would you come now, please?

Senator **Hatfield**. Thank you, Senator Grassley. We appreciate your presence.

Mr. **Porter**. Thank you, Senator Grassley.

Senator Hatfield, Senator Weicker, I am here today not only representing the national commission, but the Cooperative Education Association and the Cooperative Education Division of the American Society for Engineering Education.

Together we represent the 1,000 colleges and universities, over 200,000 students and nearly 50,000 employers who collectively constitute the cooperative education movement.

We believe the administration is pursuing the correct course in seeking to make Americans more independent, more self-sufficient, and less dependent upon the Federal Government and in striving for reduced Government spending and greater private sector involvement.

However, in seeking to eliminate support for cooperative education, the administration is acting contrary to this course of action since cooperative education is the one education program that produces those very outcomes desired by the administration. In a time of growing concern over the preparation of our work force and the quality of our education efforts, cooperative education produces experienced, relevantly trained, highly employable college students. By combining education with related work, students not only learn the realities of the adult working world, but receive up-to-date, state-of-the-art training in their field and are thus better prepared to meet the rapidly changing needs of our Nation's employers.

In the process of obtaining this practical and timely college education, cooperative education students can use their own earnings to finance much if not most of their college expenses. Unlike other means of student financial assistance, cooperative education is neither a loan, a dole or a make-work program. Value received for value given is its trademark, and useful, unsubsidized employment is a source of student's financial assistance.

Through participation in cooperative education, college students earn an average of over $7,000 a year. This enables many to graduate not only with a permanent job in hand, but largely free of long term, burdensome debt.

The 200,000 cooperative education students in postsecondary education collectively earn over $1½ billion per year. Through Federal income taxes and Social Security contributions, approximately 10 percent, or $150 million is returned to the Federal Treasury each year by these students. Obviously this more than offsets the current appropriation, $13.7 million in the fiscal year 1987 Federal budget.

Beyond its important financial aid aspect, cooperative education gives young people direction and purpose in the pursuit of their education. By understanding how their classroom learning can be applied in the workplace, students are better able to make career decisions and set career goals and are better motivated to achieve these goals.

Employers find that hiring cooperative education students significantly lowers recruiting costs, improves the retention rates of college graduates, and assists in accomplishing affirmative action goals.

In advance of permanent hiring, employers view cooperative education as a means of early access to the diminishing labor pool of young people, thus increasing their chances of being able to meet future staffing needs.

Of particular importance are the benefits of co-op to society. Cooperative education is the reinforcement of the American work ethic. It builds in young people a respect for work and for the value of money earned through work. Through participation in cooperative education, young people gain an understanding and appreciation of the American free enterprise system, and because they are allowed to be part of that system, recognize a role for themselves as responsible, contributing members of our society.

PREPARED STATEMENT

As you know, the title VIII program does not involve direct financial aid to students. Federal funds are granted to colleges and universities as seed money to enable them to initiate, strengthen and improve their programs which subsequently serve tens of thousands of students. With educational institutions presently under acute financial strain, continuance of this Federal seed money support is particularly important to help ensure that fledgling co-op programs are not eliminated before they have a chance to become securely established.

Senator HATFIELD. Thank you, Dr. Porter. We will include all of your statement in the record.

Mr. PORTER. Thank you for this opportunity.

Senator HATFIELD. Thank you for coming.

[The statement follows:]

STATEMENT OF RALPH C. PORTER

MY NAME IS RALPH C. PORTER; AND AS PRESIDENT OF THE NATIONAL COMMISSION FOR COOPERATIVE EDUCATION, I APPEAR HERE TODAY TO REPRESENT NOT ONLY THE NATIONAL COMMISSION BUT ALSO THE COOPERATIVE EDUCATION DIVISION OF THE AMERICAN SOCIETY FOR ENGINEERING EDUCATION AND THE COOPERATIVE EDUCATION ASSOCIATION, INC. TOGETHER, OUR THREE ORGANIZATIONS REPRESENT THE 1,000 COLLEGES AND UNIVERSITIES, 200,000 STUDENTS, AND NEARLY 50,000 EMPLOYERS WHO COLLECTIVELY CONSTITUTE THE COOPERATIVE EDUCATION MOVEMENT.

I BELIEVE THE ADMINISTRATION IS PURSUING THE CORRECT COURSE IN SEEKING TO MAKE AMERICANS MORE INDEPENDENT, MORE SELF-SUFFICIENT, AND LESS DEPENDENT UPON THE FEDERAL GOVERNMENT, AND IN STRIVING FOR REDUCED GOVERNMENT SPENDING AND GREATER PRIVATE SECTOR INVOLVEMENT. HOWEVER, IN ELIMINATING SUPPORT FOR COOPERATIVE EDUCATION, THE ADMINISTRATION IS ACTING CONTRARY TO THIS COURSE OF ACTION, SINCE COOPERATIVE EDUCATION IS THE ONE EDUCATION PROGRAM THAT EMBRACES THOSE BASIC ELEMENTS DESIRED BY THE ADMINISTRATION.

MY BELIEF IS BASED ON THE FOLLOWING FACTS:

...IN A TIME OF GROWING CONCERN OVER THE PREPARATION OF OUR WORKFORCE AND THE QUALITY OF OUR EDUCATION SYSTEM, COOPERATIVE EDUCATION PRODUCES EXPERIENCED, RELEVANTLY TRAINED, HIGHLY EMPLOYABLE COLLEGE GRADUATES FOR INDUSTRY. BY COMBINING EDUCATION WITH RELATED WORK, STUDENTS NOT ONLY LEARN THE REALITIES OF THE ADULT WORKING WORLD, BUT RECEIVE UP-TO-DATE, STATE-OF-THE-ART TRAINING IN THE FIELD AND ARE THUS BETTER PREPARED TO MEET THE RAPIDLY CHANGING NEEDS OF OUR NATION'S EMPLOYERS.

...IN THE PROCESS OF OBTAINING THIS PRACTICAL AND TIMELY COLLEGE EDUCATION, COOPERATIVE EDUCATION STUDENTS CAN USE THEIR OWN EARNINGS TO FINANCE MUCH, IF NOT MOST, OF THEIR COLLEGE EXPENSES. UNLIKE OTHER MEANS OF STUDENT FINANCIAL ASSISTANCE, COOPERATIVE EDUCATION IS NEITHER A LOAN, A DOLE, NOR A MAKE-WORK PROGRAM. VALUE RECEIVED FOR VALUE GIVEN IS ITS TRADEMARK, AND USEFUL, UNSUBSIDIZED EMPLOYMENT IS THE SOURCE OF STUDENTS' FINANCIAL ASSISTANCE. THROUGH PARTICIPATION IN COOPERATIVE EDUCATION, COLLEGE STUDENTS EARN AN AVERAGE OF $7,000 A YEAR. THIS ENABLES MANY TO

GRADUATE, NOT ONLY WITH A PERMANENT JOB IN HAND AS A RESULT OF THEIR COOPERATIVE WORK EXPERIENCE, BUT FREE OF LONG-TERM BURDENSOME DEBTS.

...THE 200,000 COOPERATIVE EDUCATION STUDENTS IN POST-SECONDARY EDUCATION COLLECTIVELY EARN ALMOST $1 1/2 BILLION PER YEAR. THROUGH FEDERAL INCOME TAXES AND SOCIAL SECURITY CONTRIBUTIONS, APPROXIMATELY 10% OR $150 MILLION ARE RETURNED TO THE FEDERAL TREASURY EACH YEAR BY THESE STUDENTS. OBVIOUSLY, THIS MORE THAN OFFSETS THE CURRENT APPROPRIATION OF $13.7 MILLION IN THE FISCAL 1987 BUDGET.

...BEYOND ITS IMPORTANT FINANCIAL AID ASPECT, COOPERATIVE EDUCATION GIVES YOUNG PEOPLE DIRECTION AND PURPOSE IN THE PURSUIT OF THEIR EDUCATION. BY UNDERSTANDING HOW THEIR CLASSROOM LEARNING CAN BE APPLIED IN THE WORKPLACE, STUDENTS ARE BETTER ABLE TO MAKE CAREER DECISIONS AND SET CAREER GOALS, AND ARE BETTER MOTIVATED TO ACHIEVE THEIR GOALS.

...EMPLOYERS FIND THAT HIRING COOPERATIVE EDUCATION STUDENTS SIGNIFICANTLY LOWERS RECRUITING COSTS, IMPROVES THE RETENTION RATES OF COLLEGE GRADUATES, AND ASSISTS IN ACCOMPLISHING AFFIRMATIVE ACTION GOALS. FURTHERMORE, EMPLOYERS SEE COOPERATIVE EDUCATION AS A MEANS OF TAPPING THE SHRINKING SUPPLY OF YOUNG PEOPLE, IN ADVANCE OF PERMANENT HIRING, THUS INCREASING THEIR CHANCES OF BEING ABLE TO MEET THEIR FUTURE MANPOWER NEEDS.

...OF SIGNIFICANT IMPORTANCE ARE THE BENEFITS OF COOPERATIVE EDUCATION TO SOCIETY. COOPERATIVE EDUCATION IS THE REINFORCEMENT OF THE AMERICAN WORK ETHIC. IT BUILDS IN YOUNG PEOPLE A RESPECT FOR WORK AND FOR THE VALUE OF MONEY EARNED THROUGH WORK. THROUGH PARTICIPATION IN COOPERATIVE EDUCATION, YOUNG PEOPLE GAIN AN UNDERSTANDING AND APPRECIATION OF THE AMERICAN FREE ENTERPRISE SYSTEM, AND BECAUSE THEY ARE ALLOWED TO BE A PART OF THAT SYSTEM, RECOGNIZE A ROLE FOR THEMSELVES AS RESPONSIBLE, CONTRIBUTING MEMBERS OF OUR SOCIETY.

AS YOU KNOW, THE TITLE VIII COOPERATIVE EDUCATION PROGRAM DOES NOT INVOLVE DIRECT FINANCIAL AID TO STUDENTS. FEDERAL FUNDS ARE GRANTED TO COLLEGES AND UNIVERSITIES AS SEED MONEY TO ENABLE THEM TO INITIATE, STRENGTHEN, AND IMPROVE THEIR COOPERATIVE EDUCATION PROGRAMS WHICH SUBSEQUENTLY SERVE THOUSANDS OF STUDENTS. WITH EDUCATIONAL INSTITUTIONS

PRESENTLY UNDER ACUTE FINANCIAL STRAIN, THIS FEDERAL SEED MONEY SUPPORT IS PARTICULARLY IMPORTANT TO ENSURE THAT FLEDGLING PROGRAMS ARE NOT ELIMINATED BEFORE THEY HAVE A CHANCE TO REACH THEIR FULL POTENTIAL.

IN ADDITION, ONLY A FEW YEARS AGO, THE DEPARTMENT OF EDUCATION EMBARKED ON AN IMPORTANT LONG-RANGE PROGRAM TO ACCELERATE THE DEVELOPMENT OF COOPERATIVE HIGHER EDUCATION. SINCE 1980, A LIMITED NUMBER OF GRANTS HAVE BEEN AUTHORIZED UNDER TITLE VIII, TO BE AWARDED FOR THE DEVELOPMENT OF COMPREHENSIVE, LARGE-SCALE COOPERATIVE EDUCATION PROGRAMS FOR THE PURPOSE OF ENROLLING LARGER NUMBERS OF STUDENTS. THE PROCESS, INVOLVING MAJOR INSTITUTIONAL CHANGE, IS NOT ACCOMPLISHED QUICKLY. THIS IMPORTANT TEST PROJECT FOR THE ACCELERATED GROWTH OF COOPERATIVE HIGHER EDUCATION MUST NOT BE ABANDONED IN MIDSTREAM. ONLY NOW ARE SOME OF THE CHANGES BEGINNING TO TAKE EFFECT; AND MORE COLLEGES AND UNIVERSITIES ARE BECOMING INTERESTED IN ADOPTING A LARGE-SCALE COOPERATIVE EDUCATION PLAN. A MOMENTUM HAS BEEN STARTED WHICH WE MUST NOT STOP.

THERE ARE THOSE WHO MIGHT ARGUE THAT BECAUSE OF THE BENEFITS DERIVED BY PRIVATE INDUSTRY FROM COOPERATIVE EDUCATION, THAT THIS PROGRAM SHOULD LOOK TO THE PRIVATE SECTOR FOR ITS SUPPORT. I WOULD RESPOND THAT THE PRIVATE SECTOR DOES SUPPORT COOPERATIVE EDUCATION, THROUGH THE HIRING AND TRAINING OF TENS OF THOUSANDS OF COOPERATIVE EDUCATION STUDENTS EACH YEAR. IT WOULD BE UNREASONABLE TO EXPECT THE PRIVATE SECTOR TO SUPPORT INSTITUTIONAL PROGRAMS AS WELL. THE PRIVATE SECTOR HISTORICALLY HAS SUPPORTED EDUCATION THROUGH DONATIONS FOR RESEARCH AND CAPITAL EXPENDITURES, BUT NOT FOR PROGRAM ADMINISTRATION.

WE APPLAUD THE INITIATIVE THAT HAS BEEN TAKEN BY THE ADMINISTRATION IN PROPOSING THE ENLARGEMENT OF THE COLLEGE WORK-STUDY PROGRAM AS IT SEEKS PRACTICAL MEANS TO ASSIST COLLEGE STUDENTS IN FINANCING THEIR EDUCATION. HOWEVER, WE ASK THAT THE CONGRESS GIVE URGENT CONSIDERATION TO COOPERATIVE EDUCATION AS A DRAMATICALLY MORE EFFECTIVE PROGRAM. IT IS MORE EFFECTIVE IN THAT STUDENTS ARE NOT ENGAGED IN SUBSIDIZED JOBS OF QUESTIONABLE RELEVANCE, BUT ARE PERFORMING IMPORTANT WORK, FULLY PAID FOR BY THE EMPLOYER. ALSO, UNLIKE THE COLLEGE WORK-STUDY PROGRAM, WHEREIN 85% OF THE STUDENTS REMAIN ON CAMPUS PERFORMING, IN MANY

INSTANCES, LOW SKILL LEVEL JOBS, THROUGH THE COOPERATIVE EDUCATION PROGRAM MOST STUDENTS ARE EMPLOYED OFF CAMPUS, IN THE PRIVATE AND PUBLIC SECTORS, AS PART OF THE ADULT WORKING WORLD. BECAUSE OF THIS CAREER RELATED, PAID WORK EXPERIENCE, COOPERATIVE EDUCATION STUDENTS EXHIBIT OUTSTANDING SUCCESS IN FINDING MEANINGFUL, PERMANENT EMPLOYMENT UPON GRADUATION.

IN SUMMARY, I URGE THE COMMITTEE TO TAKE A CAREFUL AND SERIOUS LOOK AT THE TITLE VIII COOPERATIVE EDUCATION PROGRAM AND CONSIDER ITS ENORMOUS POTENTIAL FOR AMERICA'S COLLEGE BOUND STUDENTS. IT EMPHASIZES SELF-HELP AND THE PARTICIPATION OF THE PRIVATE SECTOR IN HELPING TO EDUCATE OUR YOUTH. IN LIGHT OF THE TAX DOLLARS RETURNED TO THE GOVERNMENT THROUGH STUDENT EARNINGS, FEDERAL ASSISTANCE IN SUPPORT OF COLLEGE AND UNIVERSITY COOPERATIVE EDUCATION PROGRAMS IS AN INVESTMENT IN A VALUABLE ASSET RATHER THAN A DRAIN OF FEDERAL FUNDS. WHAT OTHER FEDERAL EDUCATION PROGRAM CAN BOAST THAT IT RETURNS TO THE GOVERNMENT MORE DOLLARS THAN IT COSTS? THEREFORE, WE ASK THAT THIS COMMITTEE APPROPRIATE THE FULL $17 MILLION AS AUTHORIZED UNDER TITLE VIII OF THE HIGHER EDUCATION ACT, AS AMENDED.

STATEMENTS OF:
MARY ALBERT, GEORGETOWN UNIVERSITY
SAMUEL HARVEY, GEORGETOWN UNIVERSITY

Senator HATFIELD. May I invite now Mary Albert and Samuel Harvey from Georgetown University.

Mr. HARVEY. Thank you, Mr. Chairman.

I just have two brief statements, and I will turn it over to Mary Albert.

I would just like to make a request in regard to the College Housing and Academic Facilities Loan Program, first, to urge the committee to support a loan authority level of $90 million. The need for academic facilities renovation cannot be overemphasized. It is a rather massive need at this time.

Second, the Senate authorization bill for fiscal year 1989 included a provision which would place a 10-year limit on loan eligibility for any school which received funds for renovation of a current facility. Such a rule is unfaithful to the original aims of the program. Loans were intended for those facilities which demonstrated the greatest need for renovation.

I would urge the committee to incorporate into the bill language which was included in last year's appropriation report, and I urge this because last year the Department of Education did not follow the recommendations of the report language. The precise language is included in the full text of my testimony.

Thank you.

Senator HATFIELD. Thank you, Mr. Harvey.

Ms. ALBERT. I represent the medical center, and from my testimony, I would like to extract just three summary points.

First of all, I urge the committee to reject the administration's request to tinker with the HEAL Program, the Health Education Assistance Loan Program. It is an excellent program, and the administration's efforts to change it are not necessary. We urge you to keep the program as it is.

Second, we urge that health professions training not be lumped into a single fund, but that you continue to fund separate programs, and we urge continued funding of nursing programs.

And finally, within the National Library of Medicine [NLM] appropriation, we urge that you insist that the IAIMS programs be continued to be funded. These are the integrated academic information management systems [IAIMS]. They are exciting programs, and we think their full potential must be realized, and we urge you to insist that NLM continue to fund the implementation of some of those programs.

Thank you.

Senator HATFIELD. Thank you very much, Ms. Albert, Mr. Harvey, we appreciate your presence.

I now will yield the gavel to former chairman of this subcommittee, the Senator from Connecticut, who chaired it for 6 years with great distinction, and who now is the ranking minority member of this subcommittee, and very knowledgeable on all these subjects.

Senator Weicker, it is a privilege to present to you the gavel.

Senator WEICKER [presiding]. Thank you very much.

STATEMENT OF SALLY HARRIS, PROJECT DIRECTOR, NATIONAL DIFFUSION NETWORK, NATIONAL DISSEMINATION STUDY GROUP

ACCOMPANIED BY MARY ALICE FELLEISEN, DEVELOPER DEMONSTRATOR

Senator WEICKER. In order to maintain the order, I will first call upon Sally Harris, the State facilitator for Connecticut, of the National Dissemination Study Group Program.

Ms. HARRIS. Thank you very much. It is nice to be here.

I am Sally Harris, the project director for the national diffusion State facilitator project in Connecticut. My office is based in Hamden at Area Cooperative Educational Services, and with me is Mary Allice Felleisen who is a developer demonstrator in a program from Pennsylvania.

We are representing the National Dissemination Study Group, which is the professional organization that helps the people who use the grants and operate the National Diffusion Network and the teachers that use those programs.

Thank you for inviting us to testify today. What we are here for is to ask you to use the appropriations process to increase the funding from its current level of $10.2 million to $30 million. That does sound a little lavish in this particular time where it is hard to find money at all, and there are lots of pressures to cut things, but I would like to explain why we are asking for that.

As you are well aware, this subcommittee is charged with the responsibilities, and in 1979 appropriated $14 million for the National Diffusion Network. It was subsequently reduced to $10 million and has been at $10 million since 1977. And as you are aware, it has been a rocky road even maintaining that kind of level.

If we were even keeping up with inflation, we would be at $30 million today.

This year alone, I think you are familiar with the National Diffusion Network in its charge to transfer exemplary educational programs to schools throughout the United States. This last year we initiated programs in 22,000 schools with about 2½ million students being affected with new programs this year. It is enormously successful, it is cost effective. We work with chapter I programs to increase the applicability and the effectiveness of many of those programs.

Unfortunately, we are really underfunded. Most of the State facilitator projects are one-person operations, trying to maintain on about $82,000 the activities that we are charged with. This year, in fact, in the budget process, the Texas facilitator did not even apply for funding because they weren't able to operate with the charge that they have under the kind of levels that we have.

I would like to talk to you about some particular things in Connecticut where the funding impacts directly. I think you are familiar with the Simpson Waverly School in Hartford that initiated a reading program from California this year with great success. For 6 months now the students have been using the Books and Beyond Program, which is increasing recreational reading. They have tripled the amount of reading that students have done and have made some significant gains in comprehension levels in that school. This is all the good news.

What the difficulty is is that 23 other Hartford schools want to use the program, and in the plan, with the kind of funding that we have now, it will take them 4 years to get there, and this is being repeated throughout the country.

PREPARED STATEMENT

In addition to that, through H.R. 5, we have been charged with other dissemination responsibilities, and the infrastructure at this funding level just is not strong enough in the National Diffusion Network. We think this is a really good, effective use of Federal dollars and would like your support in increasing our funds.

Senator WEICKER. Sally, thank you very much.

So do I. It is a question of convincing the rest of my colleagues, you know. We are in the middle of a 2-year budget compromise, which does not do justice to education. It is as simple as that.

Thank you very much. Thank you both.

Ms. HARRIS. Thank you.

[The statement follows:]

STATEMENT OF SALLY HARRIS

I am Sally Harris, project director of the National Diffusion Network's State Facilitator project in Connecticut, located at Area Cooperative Educational Service -- ACES -- with offices in Hamden, Connecticut. I am appearing on behalf of the National Dissemination Study Group, a non-profit, association of educators from throughout the country. The Study Group's purpose is to promote school improvement through the dissemination of educational practices that have proven to be successful.

Accompanying me is from the National Dissemination Study Group is board member Mary Alice Felleisen, from Pennsylvania, who directs a National Diffusion Network Developer Demonstrator project based in that state, "Project First Level Mathematics".

We are pleased to have received your invitation to appear before this subcommittee in support for increased appropriations in fiscal year 1989 for the National Diffusion Network (NDN).

The NDN, reauthorized this spring as a result of the passage of the Hawkins-Stafford School Improvement Act, was granted initially a $10.7-million appropriations by the Congress for fiscal year 1988, but the deficit reduction measures late last year cut the NDN's current appropriation to $10,244,000. The reauthorization measure for the NDN passed by Congress last week provides a funding *floor* of $11.2-million for the program from funds specifically allocated for that purpose as part of Chapter 2 -- Programs for Elementary and Secondary Education Improvement.

Our professional association, the National Dissemination Study Group, which represents the men and women who operate the National Diffusion Network grants, as well as educators in the schools that these programs serve throughout the country, urges this subcommittee to use this appropriations process to substantially increase the funding of the NDN -- to $30-million in fiscal year 1989.

While such an increase may appear at first lavish, it would represent a return to the original commitment made by this subcommittee nearly 15 years ago to extend to our nation's schools the opportunity to make use of the best school improvement practices. In fact, just ten years ago, in fiscal year 1979, the Congress made $14-million available for the National Diffusion Network. With cutbacks in 1980, the NDN's support was reduced to $10-million, and its support has averaged about that much each year since. In effect, NDN funds have been frozen at about $10-million/year for nearly a decade. Had the National Diffusion Network's appropriations of the mid-1970s kept pace only with United States inflation, the program would today be ***level-funded at $30-million.***

Despite the severe financial handicaps it has suffered over the past decade, the NDN has survived, largely because of the dedication of its people: the thousands of devoted project directors and staff and school teachers and administrators, who have maintained their commitment to keep alive this torch -- this national network of successful school programs, which studies have indicated may be the most successful, basic school improvement effort ever funded by the federal government.*

The National Diffusion Network is a program created in 1974 and administered first through the Department of Health, Education, and Welfare's Office of Education, later through the Department if Education's Office of Educational Research and Improvement. The NDN is designed to carry out the Congressional mandate to improve educational quality through the dissemination of exemplary programs to school districts throughout the Nation -- thus promoting and encouraging excellence in education.

The NDN operates through two basic components -- State Facilitators and Developer Demonstrators. State Facilitators, located in every state, provide information about education programs to public school districts (as well as to private and parochial schools) seeking to improve their educational practices. Developer Demonstrators are projects throughout the country that represent locally-developed, thoroughly implemented and evaluated, exemplary school improvement practices. Each program has been selected by a special federal board; this group (once titled the Joint Dissemination Review Panel, now called the Program Effectiveness Panel), which provides a thorough, non-political, expert, and objective assessment of each project, certifies the effectiveness of successful applicants.

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* e.g., Stanford Research Institute (1977); *"People, Policies, and Practices: Examining the Chain of School Improvement, Vol. VIII,"* DESSI, The NETWORK, Inc. (1982)

These exemplary school improvement practices -- nearly 450 in all have been validated as exemplary since the NDN began -- are made available for dissemination through this national system. While limited resources have meant, unfortunately, that the Education Department is only able to fund, on average, a total of about 85 Developer Demonstrator awards each year, all active, validated programs are described in a catalogue -- *"Educational Programs That Work"* -- sponsored by our professional association. The catalogue lists projects in writing, mathematics, reading, early childhood education, humanities, science, special education, bilingual and migrant education, and approximately 60 other categories.

The NDN process works like this: a school in West Virginia identifies a need in its reading curriculum; the school principal contacts the NDN's State Facilitator in West Virginia and reviews with her that need. After carefully reviewing the variety of program options available, the State Facilitator makes a recommendation of, perhaps, four appropriate exemplary reading program models. The school's leadership and instructional personnel further determine just what solution makes most sense in their classrooms and agree to "adopt" a reading curriculm project from Florida. Within a few weeks, the project trainer from the Florida program travels to West Virginia -- with costs shared by the school, the State Facilitator, and the Developer Demonstrator project -- and, over a three-day period, trains 15 of the school's 22 teachers. The teachers begin implementing the curriculum immediately, and the trainer returns for follow-up twice during the next academic year. Assessment scores show that the reading gains of the children in the West Virigina school soar, as they have in the original Florida site and in each of the program's other "adoption" sites throughout the country.

The initial cost of *development* of a project disseminated through the NDN is often $500,000 or more, yet the entire cost of successfully replicating the successes of that project in another local school often costs only a few thousand dollars, sometimes even a few hundred dollars -- costs shared by the Developer Demonstrator, the State Facilitator, and the local school district.

Essentially the National Diffusion Network is successful American teachers helping other teachers duplicate their achievements.

In 1975 about 15,000 teachers, serving some 375,000 students, were trained by National Diffusion Network grantees. By the mid-to-late-1980s, an average of over 60,000 teachers a year -- in 22,000 schools, reaching an estimated 2,500,000 U.S. school children -- are provided new skills through the training provided by the dedicated staff of validated NDN projects across the country.

The NDN is an enormously effective and cost-efficient system for the improvement of America's schools. Long before the phrase "What Works" became a popular phrase in the Education Department, the National Diffusion Network was proving that school programs that work can be transplanted elsewhere with a *duplication of the same successes* (for example, in student achievement) achieved by the original developer. For the cost of the development of one reading program, a whole school curriculum can be recreated using NDN projects -- as schools have demonstrated in at least five states across the country.

Not only is the NDN, itself, cost-effective, but it has the extraordinary quality of actually enhancing the cost-effectiveness of other federally-funded education programs! A good example is Chapter I: over the years the National Diffusion Network has made Chapter I a more cost-efficient program in at least two ways. First, to meet an educational need in a particular Chapter I-eligible district, a local administrator can be assured of a successful solution for a very modest investment by adopting one of the dozens of Chapter I-appropriate NDN projects. It would be difficult to calculate how many hundreds of thousands of dollars have been saved because local Chapter I and other federal funds were efficiently used for adoption or adaptation rather than for development.

A second way that the NDN has aided a program like Chapter I is by serving as the natural dissemination vehicle for successful programs that *are* developed with Chapter I funds. A rich investment in development is virtually wasted if a new program has a one-time use and is then abandoned; it is analogous to a classic novel been created, read by a single person, and then destroyed. New, effective projects, like well-written literature, should be available to all who can -- and wish to -- benefit from them. The NDN serves as the nation's bookstore or lending library of school improvement resources; it is well stocked with dynamic educational tools that might otherwise be unused.

A 1981 Congressional report on the program called the NDN one of the most successful examples of a sound federal investment in education. But this success has been earned at a price. It is the price to participants of maintaining and upgrading a system that has become, with time, seriously underfinanced. The average

State Facilitator project grant was $84,500 in 1977; last year it was $82,000, a *reduction* of $1,500 after 10 years. Factoring in the real inflationary increases that each of these projects has faced for staff, travel, and office costs, that $82,000 grant is today worth about $36,000. Likewise, in 1977 dollars, today's Developer Demonstrators must make do with grants averaging $24,500.*

Very few business people can resourcefully run a national project on $25,000 a year. And these *are* businesses. The NDN projects are located in local schools, in state departments of education, in non-profit agencies, and in institutions of higher education. But these grantees, like the corner grocery store, are expected to get the job done, pay their staffs and their bills, and come out even by year's end. It isn't easy. Facilitators are expected to meet the increasing demands of local schools throughout an entire state. Imagine attempting to serve all the schools throughout Texas on a State Facilitator budget of $100,000 a year. The incumbent Facilitator in the Lone Star state couldn't. That agency this year declined to reapply for Education Department funding -- it simply could not *afford* to stay in the NDN system any longer.

Developer Demonstrators are expected to be responsive to the needs of schools throughout the whole country. Yet, in real dollars, these projects survive -- and barely -- on an annual amount from the federal government that, in many cases, barely pays the salary and fringe benefits of *one* staff member: that is exclusive of travel, expenses, administration. Each year several veteran Developer Demonstrators decline to reapply for NDN funding. Some seek independent funds instead; others simply close up shop.

The newsletter I edit for our professional association has taken to publishing a regular feature called "Stayin' Alive" -- it lists each month strategies sent in by our members -- ones that they use just to keep their projects afloat. Here are examples: • "Cut staff (to one person)". • "Eliminate *all* secretarial support". • "Job-share with other programs in my agency". • "Diversify our operations (to an extent that it becomes hard to do our primary job)". • "Provide no staff salary increases for the third straight year". • "Work, myself, 20 days last year without pay". • "Eliminate our statewide project newsletter, the only regular link to schools in our large state that we've had". And so on.

Why do these people carry on? There are dozens of veterans in the NDN system, like Mary Alice Felleisen and myself, who have stuck it out for a decade or more. As frustrating as it often is, these dedicated educators have jobs where they can make a difference; where their intervention means that a child, who couldn't read before, now can; that an eager but poorly trained teacher now has the tools she needs; that a whole school can be dramatically transformed. These professionals are hooked on the NDN system because it works. But, because of its financial problems, it is not working as well as it could.

Among the other consequences to underfunding of the National Diffusion Network is a serious depletion of the pool of new projects entering the system. For a newly developed program in Wisconsin to become validated and part of the National Diffusion Network, it needs to be evaluated and to go through multiple other assessment steps, make several applications, then, if successful at *every* stage, receive a Department of Education grant to do national dissemination work for a total of about $50,000-a-year, which might just pay its basic costs, never mind travel. The first job that is likely to face a new Developer Demonstrator after award of the grant is devising a strategy to raise more funds!

Frankly, there is now simply too little incentive for innovative program developers in schools to go through that process. As a result, although new, exciting programs continue to be developed in our nation's schools, the reservoir of potential new NDN projects is dangerously low. Each year the Education Department provides funds to a special, technical assistance contractor, whose principal job is "search", that is, scouring the country for new programs for the NDN.

Like any retailer, NDN State Facilitators need to be responsive to new customer/school needs. If the newest need is for bilingual instruction in Vietnamese in public schools in Oregon, the Facilitator there wants to be able to respond. In fact, it can't; there are yet no Vietnamese instructional programs in the NDN.

We recognize that we appear before you at a time of enormous concern for the federal deficit and the cost-savings that responsibly accompany our national response to this crisis. Yet, we boldly request that the National Diffusion Network's budget be substantially increased -- from its current $10.24-million, and its newly authorized floor of $11.2-million, to $30-million.

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*See attached chart

A part of the recently approved (H.R. 5) legislation authorizes the National Diffusion Network for the first time ever to become the Department's official program dissemination function for *at least* the following Education Department initiatives: (1) Even Start; (2) Secondary School Programs for Basic Skill Improvement and Dropout Prevention and Reentry; (3) Title VII, Bilingual Education., *and* (4) Fund for the Improvement and Repform of Schools and Teaching. The authorizing committees have, in effect, said: *As new programs are developed under these new initiatives, the exemplary practices should be formally disseminated through the NDN.* We are all quite excited with this designation, and, I assure you, our members are eager to welcome into the NDN such newly developed programs.

But the infrastructure of the National Diffusion Network will not likely be able to support the added burden which this legislative initiative will naturally create. With essentially no increase in appropriations for a decade, the very viability of the current NDN system is in question. It is unlikely that it can now take on new programmatic responsibilities.

Yet, the education committees of the House and Senate did not elect in HR 5 to authorize specific appropriation levels for the National Diffusion Network in each of the places they indicated they wanted the NDN employed. The only place we can go to seek support that will permit the NDN to do its principal work, plus begin to rebuild the system's infrastructure so as to begin the process of preparing for the new programmatic additions, is through the general appropriations for our program.

We come to ask for the first time for an increase in support for the NDN. You can make no better investment in our nation's schools than in the National Diffusion Network. It was created to build upon already-developed success, and it is a success story of its own. But it cannot get the job done at its current level of support.

Quite often I get inquiries from Connecticut teachers about the possibilities of adopting an NDN program. Early in the process of our discussions we develop a budget, one which usually includes travel and expenses for the Developer Demonstrator trainer, substitute fees, and teacher materials. Far too often adoption of the program of their choice -- given the available, combined resources of the our State Facilitator project, the Developer Demonstrator project, and the school -- is deemed impossible simply because of cost. I always promise them to try to find a solution for this dilemma in a subsequent academic year, but, in the meantime, the students in that school cannot benefit from the NDN program which would meet their needs.

Unfortunately, this scenario is not unusual. It is played out every day by NDN projects across the country. Many State Facilitator projects are simply afraid to continue publicizing the existence of their services. Their current resources are exhausted each year by delivery of services to schools that already know about them and are returning for other help or for followup assistance. This means that many other schools with real needs in every state are not even being reached.

The $10-million support for the NDN in 1977 is just not enough for us to do the job in 1988. (Your colleagues on the Education Committee realize that -- their new, reauthorization of the NDN directs that "*not less* than $11.2-million" be expended for the National Diffusion Network.) We *were* able to get the NDN job done effectively in fiscal year 1977 for the $10-million then provided for that purpose. Factoring in U.S. inflation, that $10-million represents roughly $30-million today. We could get the job done well today with such an appropriation, and we respectfully ask you to restore to the NDN that level of support.

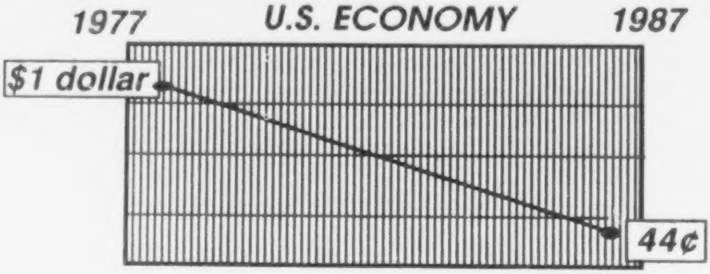
The dedicated NDN program directors and staff throughout the country are prepared to do the work, and America's schools are clamoring for our services. We ask you to arm us with the appropriate means to help them.

Thank you.

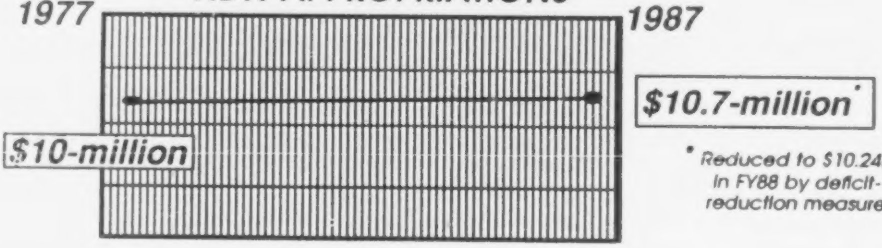
[Attachment]

FINANCIAL PROFILE

Effects of inflation on the
U.S. ECONOMY



NDN APPROPRIATIONS



* Reduced to $10.24M in FY88 by deficit-reduction measures

Average 1977 SF grant: $84,500
...in 1987: $82,000 — actual value, given inflation: $36,000

Average 1977 DD grant: $50,000
...in 1987: $55,500 — actual value, given inflation: $24,500

Summary:

As a result of level funding over the past decade, which has seen the buying power of the U.S. dollar fall by some 44%, National Diffusion Network projects -- both State Facilitators and Developer Demonstrators -- are financially crippled. Several have gone out of business. Nearly all broker service dollars from multiple sources, severely straining already limited staff resources. Almost none are able to meet the demand for NDN school improvement services.

If the NDN is to be able to meet the educational challenges of America's schools in the years ahead -- indeed, if many of its vital components are to survive -- additional appropriations are desperately needed.

The National Dissemination Study Group, the professional association of NDN educators, respectfully requests that Congress appropriate $30-million for the NDN in FY1989.

STATEMENT OF STEPHEN J. TRACHTENBERG, PRESIDENT, UNIVERSITY OF HARTFORD, ON BEHALF OF AMERICAN COUNCIL ON EDUCATION

Senator WEICKER. Our next witness is Stephen Trachtenberg, president of the University of Hartford, representing the American Council on Education.

Steve.

Mr. TRACHTENBERG. Senator, it is good to see you.

Senator WEICKER. Nice to have you.

Mr. TRACHTENBERG. It occurs to me that it may perhaps be most useful for me to talk about what I know best, namely, the University of Hartford.

I presently serve as its president. The institution is located in Hartford, in West Hartford, and in Bloomfield, CT, and enrolls approximately 7,600 students who come from around the Nation and the world.

Our commitment to educational access for these young people is in desperate need of enhanced Pell and SEOG support. Let me just give you one paragraph that I think tells the story.

Since the 1985–86 fiscal year at the university, we have seen a shift in the types of funds distributed to students with the university now supplying almost 50 percent of all student financial assistance. Of the $11.5 million administered through financial assistance, 49 percent was actual grant money provided from tuition revenue, that is to say, essentially the university is doing what the Federal Government used to do, taxing the wealthier students and providing the assistance to the poorer students. The university contributed over $5.6 million in grants. The State of Connecticut provided about $1 million, while the Federal Government allocated $776,000 in grant funds, $280,000 in college work-study, and the great bulk of the Federal money came from Perkins and GSL funds, $3.8 million in loans.

This current academic year, financial aid was surpassed at the university only by instructional expense, and indeed, it represented over 10 percent of the university's total operating budget. Those funds come from scholarship programs developed in the last few years for financially needy students through our capital campaign and through philanthropy, mostly from the greater Hartford area.

It will come as no surprise to you, Senator, that Hartford has large and deep pockets of poverty and a very large minority population that faces growing obstacles in its quest for educational opportunity, and despite our considerable efforts and our determination to assist these students, students who come from some of the most economically distressed neighborhoods and communities in our State, we find that we are losing that battle, and many constituents who would like to come to the University of Hartford because we have the right academic program for their background and for what they need and want, are obliged either to go elsewhere or go nowhere.

PREPARED STATEMENT

We are a typical tuition driven institution, dependent on earned income from tuition for more than 70 percent of our operating expenses. We have been managing, I must tell you with some pride, to balance our budget for the past 11 years, but it gets harder and harder.

I will submit for the record my testimony, and I will not take any more of your time.

[The statement follows:]

STATEMENT OF STEPHEN J. TRACHTENBERG

Thank you for the opportunity to present the recommendations of the higher education community for FY 1989 Education Department appropriations. At the outset, I want to express our deep appreciation to Chairman Chiles and Senator Weicker for their vigorous efforts to win acceptance of the Chiles substitute to the 302b allocation formula recently adopted by the full Committee. Thanks are also due to Senators Proxmire, Inouye, Harkin, and Specter, who voted in favor of the Chiles substitute.

We ask for increases totalling $885 million over FY 1988 to make progress in two top-priority areas:

Priority #1: Increase Grant Assistance to Needy Students

Our highest priority is two-fold: an increase for Pell Grants and for Supplemental Educational Opportunity Grants. The combined cost of the increases we propose is $785 million. These two programs are the building blocks of educational opportunity for needy students, and the vehicles for reversing the decline in minority participation in higher education.

In recent years loans have become the dominant form of federal student aid, as the value of grant awards has failed to keep pace with inflation. Failure to approve an increase in the Pell Grant maximum and to allocate adequate support for SEOG will perpetuate the cycle of loan dependency for the neediest students who aspire to postsecondary education.

An increase in the Pell Grant maximum is needed to help restore the value of the award for the neediest students. A $2,400 maximum would cover 30 percent of average costs and provide increased benefits for all 3 million recipients in Academic Year 1989-90 (the current $2,200 maximum will cover 29 percent of costs in AY 88-89). For students in public institutions, where the average cost in Academic Year 1989-90 will be $6,500, it would cover 37 percent of expenses; in independent institutions, where the average cost will be $14,000, it would cover 17 percent. We estimate that an increase of $585 million would fully fund a $2,400 maximum, including first-time eligibility for less-than-half-time students.

It is important to remember that many students do not receive the maximum award, and therefore have an even smaller percentage of costs covered by their Pell award: if the maximum is $2,400 for the neediest student, the award for a student from the typical family of four with one in college and annual income of $20,000 would approximate $1,600.

Thus, increases in other federal aid programs are necessary to help needy students make up the gap between total costs and family resources. We recommend a $200 million increase for SEOG, and inflation increases for College Work-Study, Perkins Loans, and State Student Incentive Grants.

A significant increase in SEOG is essential to reduce the debt burden of low-income students (who receive priority for these awards) and to recognize the needs of students attending higher-cost public and independent institutions. Despite the importance of increasing this program in tandem with increases in the Pell Grant, the SEOG appropriation has declined 24 percent in constant dollars since 1980.

Substantial increases in federal student aid are urgent, because the number of very low-income students is increasing dramatically. Between 1980 and 1985, Pell Grant recipients whose families are too poor to make any financial contribution to their educational costs increased from 1.17 to 1.54 million, or over half of all recipients. To cover these new poverty-level students, Pell Grant program costs have risen substantially, making it more difficult to increase the maximum award and generating greater demand for campus-based aid and Guaranteed Loans.

During the same period, enrollments in the collegiate sector remained relatively stable, while enrollments in the proprietary sector--which includes large numbers of very low-income students--grew rapidly. As rising program costs made it more difficult to fund regular increases in the maximum award, increasing numbers of eligible students with family incomes above $20,000 have been dropped by the Pell Grant formula, which eliminates students at the top range of eligibility when the maximum is not increased. Accordingly, Pell Grant recipients in the collegiate sector have declined from 2.5 million in 1980 to 2 million in 1986, while appropriations for the program have risen 62 percent.

Priority #2: Increase Selected Categorical Programs

We also request increases totalling $100 million for the following programs which serve special national purposes:

* Title III Developing Institutions addresses the specific developmental needs of historically black colleges and other institutions with large concentrations of minority and low-income students. Additional funding for this program is particularly important in the light of growing concerns that the educational system is not preparing adequate numbers of minority and low-income youths for careers in the sciences, teaching, and other professions.

FY 1988 Supplemental Request: We also urge the Subcommittee to provide a $15 million supplemental appropriation for Title III-A, to restore its FY 1987 funding level and thus prevent the elimination of new awards and a 40 percent reduction of continuing awards for four-year institutions serving large populations of needy and minority students.

* Special Programs for the Disadvantaged (TRIO) are of proven value in encouraging the participation and retention of disadvantaged youth in college. These programs--Upward Bound,

Talent Search, Special Services, Educational Opportunity Centers, and staff training grants--have eroded in value in recent years due to rising costs. We especially ask that the Education Department be directed to fund the Ronald McNair Post-baccalaureate Achievement Program, as specified by the conference report on the FY 1988 Continuing Resolution.

* **Title IX Graduate Education programs are a key component of the nation's effort to sustain its teaching and research capacity, and to prepare for the sharp increase in demand for faculty when both student enrollments and faculty vacancies increase in the mid-1990's.** Three fellowship programs need increases simply to maintain their current scope by providing for new and continuing awards: the **Harris Fellowships**, which expand postbaccalaureate opportunities for women and minorities; the **Javits Fellows Program**, which encourages exceptionally talented students into graduate programs in the arts, humanities, and social sciences; and the new **National Needs Program** which provides training grants to reverse the decline of U.S. students pursuing teaching and research careers critical to the nation.

The new **Part A** program for talented minority undergraduates should also receive an increase because it addresses one of the most serious problems confronting graduate education: the persistent underrepresentation of minorities.

* **Foreign Languages and Area Studies contribute directly to strengthening America's economic competitiveness.** Increased funding is needed to expand the knowledge and talent developed in these programs, to improve understanding of other languages and cultures, and to help business compete more effectively in international markets.

Senator WEICKER. Steve, thank you very much.

I know that you have done an outstanding job at the University of Hartford, and I think the city of Washington, and more particularly George Washington University, are going to be very fortunate to have you down here and at the helm of that institution of learning.

Mr. TRACHTENBERG. Well, thank you very much. I look forward to seeing you.

Senator WEICKER. Well, I know one thing also. You will be knocking on everybody's door down here with the same frequency that you do up there, and I think that is a good thing.

Mr. TRACHTENBERG. Thank you.

Senator WEICKER. I think you are a very eloquent spokesman for the cause of education.

Mr. TRACHTENBERG. Thank you. I want to thank you for all the good that you have done for education and for people in need in this country during your several terms in office, and I want to wish you well.

Senator WEICKER. Thank you very much.

STATEMENT OF GERALD N. TIROZZI, COMMISSIONER OF EDUCATION, STATE OF CONNECTICUT, ON BEHALF OF THE COUNCIL OF CHIEF STATE SCHOOL OFFICERS

Senator WEICKER. The next witness is Gerald Tirozzi, from the Connecticut Department of Education, representing the Council of Chief State School Officers.

Commissioner, it is a special pleasure to welcome you. I want to say that in terms of professionalism I admire you, but probably more importantly in terms of courage and standing up and saying what needs to be said, I admire you even more, and it is nice to have you before the committee.

Mr. TIROZZI. Thank you, Senator. It is nice to hear those words.

First, I would like very much to thank the Appropriations Committee for your support in the past, and of course, Senator Weicker, for your continued support of public education across this country. It is truly appreciated.

I am here today to speak briefly on H.R. 5 which is now Public Law 100-297, which represents the reauthorization of all elementary and secondary education programs, and to talk about H.R. 3, the omnibus trade legislation. We feel these are real investments in human resources in this country, and they focus on the needs and the potential of our children and our adults who live in poverty.

Our council in particular strongly supports the $1.4 billion increase for educational priorities in H.R. 3 and ongoing commitments to such programs as handicapped education, and again, reinforcing the need to address the $1.4 billion increase. I would also like to stress our highest priority this year is looking at children at risk of failure in our schools. The council has made a strong commitment to hopefully virtually assure that every youngster will graduate from high school by the year 2000. And in order to meet your need, which is Congress' need and commitment to ensure that we will serve 100 percent of all eligible chapter 1 children, we urge an increase of $500 million above inflation for chapter 1 as the top priority for fiscal year 1989 appropriation.

We would also hope we can gain your support for the new chapter 1 program improvement. This will require States and local education agencies to identify each school where we have not seen improvement or we see a continuing decline in improvement, and to form a partnership of cooperative effort to address the needs of those schools.

To do this further, we ask that we have authorization to spend one-fourth of 1 percent of the total chapter 1 allocation, which translates into approximately $12 million, to accomplish this end. We think this is a very creative part of the legislation and hope you would support it.

I cannot state strongly enough that we are still looking at a significant portion of approximately 99 percent going in direct services to students. So what we look for in this particular area, while it is a very small amount of money, is very much necessary.

I would also note that States are really ready to go in this area, and Senator, you may be familiar with the program we have in Connecticut called the Priority School District Program. We set aside about $3 million, we identified the 20 lowest scoring communities in the State, and for the past 3 years we have had an excellent partnership, and we already are beginning to see results.

And we do this all with State money. I make that point, and I think the Federal Government could play a significant role in this area.

Also, it is essential, that as the reauthorization is considered, that the 1 percent of the total chapter 1 dollars for States to administer the program be, of course, continued. We are responsible for all monitoring, all evaluation, and essentially all general assistance to the local districts, and this would translate into approximately $48 million of the total request, again pointing out that 99 percent of the share goes directly to districts.

PREPARED STATEMENT

And the last point I want to make, we support the inflation offsets plus real growth for all programs which serve populations at risk, and a particular emphasis on our handicapped youngsters, our limited English proficiency youngsters, and our adults in need of basic education.

Thank you.

[The statement follows:]

STATEMENT OF GERALD N. TIROZZI

Mr. Chairman, distinguished Members of the Committee, I appreciate the opportunity to testify on behalf of the Council of Chief State School Officers (CCSSO), representing the nation's commissioners and superintendents of education. Due to time limitations and the number of witnesses you will be hearing from today, I will keep my remarks brief, and submit my testimony in full for the record.

Very recently, Congress completed several years of dedicated work on the reauthorization of all elementary and secondary programs by passing H.R. 5 (now P.L. 100-297), the Hawkins/Stafford School Improvement Act of 1988. Congress has also devoted three years of study and debate to omnibus trade legislation, H.R. 3. These landmark measures represent a real investment in human resources, especially directed to the needs and potential of children and the growing numbers of individuals in poverty. These measures reflect the reality of budget and trade deficits that are stifling our economy and limiting our spending options, by authorizing modest growth in existing programs and tightly targetted new initiatives.

The nation's chief state school officers strongly support commitment of a $1.4 billion increase to education for FY 1989. We are pleased the final budget resolution provided an adequate ceiling for education, training and social services to address the education priorities in H.R. 5, and H.R. 3, as well as on-going concerns such as education of handicapped children. CCSSO commends your diligence in seeking adequate funds for the vital human service programs under your jurisdiction in the process of allocating funds among the various appropriations subcommittees. We urge you to commit a $1.4

billion increase to education in your FY 1989 bill, as this is the minimum necessary to realize the programmatic commitments Congress has made to education. These programs provide our populations most at risk of school failure and welfare dependency an opportunity for educational attainment and success, as well as enhance the quality of instruction, research and statistics.

The Council's highest priority is children at risk of school failure. In November of 1986, the Council unanimously adopted a goal of assuring that virtually every child graduates from high school by the year 2000. We continue that emphasis on the needs of students at greatest educational risk this year through our focus on early child care and child development programs. Accordingly, our highest priority in the fiscal year 1989 appropriation for education is for Chapter 1, which forms the foundation of compensatory education services to disadvantaged students, to receive the full authorization level of $500 million above inflation. This is the critical first step toward the goal Congress established in H.R. 5 of serving all eligible Chapter 1 students by 1993. This increase will enable funding of concentration grants to the nation's poorest rural and urban districts and new initiatives like Even Start, dropout prevention, and the secondary schools basic skills program.

CCSSO is pleased that Congress coupled the commitment to expanding Chapter 1 services with an effort, for the first time in the two decades of the program's operation, to assure that every child is being served in an effective Chapter 1 program. The reauthorization of Chapter 1 contains provisions for state and local education agencies (SEAs and LEAs) to identify schools where there is no improvement or a decline in aggregate student achievement. The new "program improvement" process will enable these schools to receive special attention through specific plans and technical assistance from the local level. The provisions also assure that if this assistance does not bring the desired results, there will be joint attention from the local and state education agency in planning and providing the technical assistance necessary for school improvement. In fact, the legislation requires each state to provide an on-going effort and resources to bring about the gains in achievement that are the norm, and that we expect, for all Chapter 1 programs.

The legislation authorizes one-fourth of one percent of the total Chapter 1 appropriation for states to provide the required technical assistance to local education agencies and schools in need of improvement. Accordingly, a FY 1989 appropriation of $4.8 billion for grants to states and local education agencies would authorize $12 million for program improvement activities. None of the funds can be used for administrative purposes. None of the funds will be diverted from direct services to Chapter 1 eligible children. All of the funds must be used in ways that local and state education agencies agree will be most effective. Although H.R. 5 contains other authorizations for technical assistance centers and regional labs and centers to provide technical assistance for program improvement, the state education agency is the only entity required to provide this assistance. SEAs and LEAs will decide, in the state educational improvement plan and plans for individual schools, the most efficient way to deliver the services--through higher education institutions, regional labs and centers, or direct services by state personnel.

The states are actively involved in the process of implementing the new program improvement provisions. We are ready to go. A number of states, including Connecticut, have already identified schools in need of improvement as part of their reform effort. Such schools receive special assistance -- such as teacher training, activities to enhance principal leadership, and curriculum development -- to enhance student achievement. By adding this program improvement component to Chapter 1, Congress has assured that the children participating in the nation's largest compensatory education program and those at most risk of school failure are participating in programs that are best able to result in gains in their achievement.

From the inception of Title I through fiscal year 1988, ninety-nine percent of Chapter 1 funds have been allocated to direct services to students at the local level. The new program improvement provisions do not change that balance. The additional one-fourth of one percent of total state and local dollars will be used for direct assistance to LEAs and schools targetted to those school sites where the anticipated gains are not occurring. CCSSO is most anxious to go forward with the new program improvement activities authorized by the Section 1405 and request that you provide this funding.

The authorization for state education agencies to administer the program remains at one percent. We ask that this Committee provide the full one percent for state responsibilities for program operation, monitoring, evaluation, and general technical assistance. $48 million to assure compliance and quality in a $4.8 billion program is the minimum necessary for responsible accountability.

The Council believes all programs that serve at risk populations--the handicapped, children with limited English proficiency, adults in need of basic education, and other special populations--must receive offsets for inflation plus real growth. This is particularly important in the case of education for the handicapped. Federal law guarantees educational access to public education for handicapped children. In fulfilling their responsibilities under the law, state and local education agencies need a strong base of federal support for special education services, as well as teacher training and personnel development. It is critical that adequate FY 1989 appropriations be provided for the preschool programs authorized for handicapped children. Early intervention for these children is a very cost-beneficial investment.

New initiatives focused on the role educationally disadvantaged individuals must play in a competitive economy and democratic society, such as workplace literacy and dropout prevention, must be funded. By supporting these programs of educational access and opportunity, your Committee will be advancing initiatives of Connecticut and other states. For example, Connecticut's Priority School District Grant Program, which I mentioned earlier, allows the 20-25 school districts where student achievement is lowest to volunteer to develop and submit a plan for improved student performance and to receive intensive technical assistance from the State Department of Education in implementing the plan. This program has proved so successful and popular that a similar initiative aimed at dropout prevention through targeting resources on those districts with the highest dropout rates has now been authorized.

As important as programs that promote educational equity are those that enhance educational research and statistics, the barometer of quality in our schools. The Center for Education Statistics (CES) authorization in H.R. 5 provides for essential strengthening, at a critical time, of our information on how the schools are doing. The authorization of $42.3 million includes $9.5 million for expansion of the National Assessment of Education Progress toward state-by-state testing. This is the minimum level needed to implement this expansion adequately.

The CES authorization also includes a cooperative, state-federal program for provision of basic school statistics, providing support for such a statistical program to the states for the first time ever. This program should be earmarked within the appropriation so this cooperative effort can proceed smoothely and effectively. At least $4 million per year should be set aside for it. Both the NAEP expansion and the cooperative statistics program have been actively supported by Ohio, Mississippi, Kentucky, and many other states.

We would also call your attention to the need for adequate, and preferably separate appropriation of salary and expense funds for the Center for Education Statistics. H.R. 5 includes many provisions to strengthen this agency which cannot be carried out without these organizational resources.

Finally, we support adequate federal investment in educational quality. We urge you to restore Chapter 2 to 1987 levels plus current inflation, to allow states and local education agencies to direct resources to innovation and the needs of special populations. The H.R. 5 reauthorization targets this program by identifying a series of clear national priorities for which the funds may be spent.

We also recommend that the new mathematics and science program receive its fully authorized level for fiscal year 1989. The

Education for Economic Security Act has provided limited, but effective funds to leverage innovative teacher training projects since FY 1985. H.R. 5 contained an important transition from the original start-up program to a balance of broader support to local districts and state initiatives at the elementary and secondary and postsecondary levels.

Again, I appreciate this opportunity to express our Council's support for your work to adequately fund federal education programs and thank you for your consideration of our recommendations.

Senator WEICKER. Commissioner, let me just clarify one point.

The $500 million additional that you are seeking, does that refer just to the grants, the basic grants program, or is that the total for chapter 1?

Mr. TIROZZI. That is the total for chapter 1, I believe, total.

Senator WEICKER. Total. OK.

Well, again, I have to say that unless lightning strikes, we are all bound by this great compromise agreement that was reached, which I was opposed to, which pretty much handicaps us in trying to go ahead and give additional allocations to many areas of education and science, and we will do our best, but I am not going to hold out a great deal of hope for a figure such as that.

Mr. TIROZZI. Well, thank you, Senator, and we make our best efforts.

Senator WEICKER. We will try, but sooner or later, you know, somebody is going to have to come up here, not come up here but sort of have the American people put education at the top of the agenda. I have heard everybody talking about everything during this political campaign. I am talking about both parties, Presidential candidates. I do not hear much on education.

If they ain't talking about education now, they are not going to be talking about it when the next Congress convenes, I can tell you that right now.

So this is the time to say it.

Mr. TIROZZI. Thank you, Senator.

Senator WEICKER. Thank you very much.

The next witness is Gregory Humphrey, the director of legislation of the American Federation of Teachers.

Is Mr. Humphrey here?

[No response.]

STATEMENT OF GARY TIMMONS, LEGISLATIVE SPECIALIST, NEA GOVERNMENT RELATIONS, ON BEHALF OF THE NATIONAL EDUCATION ASSOCIATION

Senator WEICKER. The next witness is Gary Timmons, the legislative specialist representing the National Education Association.

Mr. TIMMONS. Thank you very much, Mr. Chairman. I am here representing Kenneth Melley, director of the Division of Government Relations at NEA who was unfortunately unable to be here today.

I believe the text of our written statement has already been provided to you, and with the understanding that it will be inserted in its entirety in the hearing record, I will just outline several of its key points.

It is the conviction, Mr. Chairman, of the National Education Association that the American system of public education is facing demands unprecedented in this Nation's history. Among many factors contributing to this pressure is the fact that numbers of disadvantaged students, particularly in urban school systems, are growing rapidly, and the degree of these students' disadvantage is greater than it ever has been before.

Second, societal institutions which have traditionally worked to support and reinforce the mission of schools are being eroded, often to the degree that in many communities schools are virtually alone in coping with the diverse needs of their students.

Schools are attempting to prepare students for work in the next century in a work force and an economy that will be far more fluid and demanding than that of today. The 1.9 million teachers and education support personnel who are members of our organization stand ready to meet these challenges but cannot do so without desperately needed Federal resources.

Unfortunately, as you know very well, what we have seen is a decline in Federal assistance in a whole range of programs, including those which serve disadvantaged students, those with limited proficiency in English, and the handicapped.

Mr. Chairman, we are grateful for the leadership that you and the subcommittee have shown in attempting to allocate resources which underscore the importance of education to the current and future well being of the citizens of our Nation, but we are here to say that your help is needed now as never before.

Of the 40 million students currently enrolled in public elementary and secondary schools, 1 in 2 has a mother in the labor force, 1 in 4 is poor, 1 in 4 is at risk of becoming a teen parent, 1 in 6 has no health insurance, 1 in 7 is at risk of dropping out of school, 1 in 8 has limited proficiency in English, and 1 in 10 is physically or mentally handicapped.

A few weeks ago Congress overwhelmingly affirmed its commitment to a vigorous and strengthened federal role in education by enactment of H.R. 5, the Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988, into law. This landmark legislation reauthorizes and expands virtually every Federal program for elementary and secondary students.

The subcommittee must follow through on this commitment by fully funding the programs in this important law.

Mr. Chairman, we understand that the full Appropriations Committee may be meeting this week to add some $500 million to the current subcommittee allocation for education. We are very pleased with this decision because these additional funds will bring the appropriation for education discretionary programs more into line with the assumptions in the budget resolution that was approved in the Senate this week.

PREPARED STATEMENT

In shaping our fiscal year 1989 Labor-HHS-Education appropriation, Congress must restore funds lost to education programs as a result of last year's conference committee action. It must provide at least sufficient funds to keep pace with inflation for all education programs, and provide additional funding to restore education services lost over the past 7 years as a result of budget cuts, inflationary erosion and increased needs.

Thank you very much.

[The statement follows:]

STATEMENT OF GARY TIMMONS

I am Gary Timmons, legislative specialist in Government Relations for the National Education Association, which represents 1.9 million education employees throughout the nation in elementary, secondary, vocational, and postsecondary schools. We appreciate this opportunity to comment on an issue of the utmost importance to the future of this nation: the level of federal assistance provided to promote excellence and equity in America's educational institutions.

Public education in this country is in the midst of a crisis. A crisis of confidence. A crisis of competing needs. A crisis that challenges our nation's ability to live up to each and all of our commitments, ambitions, and dreams.

As in any crisis, the first reaction is generally confusion: a lot of fingerpointing, a lot of evasions and denials, a lot of quick-fix attempts to make the problem go away.

But it will take much more than quick fixes to address the economic, social, and political conditions that challenge our ability to make progress in the national drive for educational excellence and equity. Without significant federal assistance, the essential conditions that shape our society and our schools will not improve, and in many cases they will get far worse.

The first essential problem--or challenge, if you will--is the absence of social programs that help a growing segment of our nation, the underclass, cope with the human problems of a lack of access to good nutrition, health care, and family support and stability.

A second basic challenge is a public education structure that includes some federal mandates, some state mandates, some local mandates, often without any coordination or cohesion of purpose. Within that structure, education employees often have little flexibility to deal with the incredible diversity of student needs, learning styles, interests, and abilities.

Finally, a central challenge facing the public schools is change: changes in the economy, changes in the society, and changes in the American family. We as a nation have not had time to assimilate all the changes that have come about up to now, but we don't have the luxury of waiting. We, the public schools and our society as a whole, must prepare now for the world that faces us.

Our members welcome the challenge of using our system of universal public education to help shape the economy, to help maintain the vitality of our democratic traditions, to help make lives better for the millions of students who come to class hungry, sore, alienated. We see our work, not as a 9:00 to 5:00 job, but as a mission, a mission that embodies the highest ideals of our national traditions.

But we need your help.

Our national education policy is defined by the scope and range of federal education programs. And frankly, in recent years, that policy has been "We want to help, but not too much." We've seen a marked decline in federal assistance for programs to serve disadvantaged students, students with limited proficiency in English, the handicapped. We've seen a marked decline in resources to strengthen programs that will ensure that our nation's citizens have the skills in math, science, foreign languages, writing, and other core curriculum areas we need now and in the future. We've seen a steady erosion in programs that meet the human needs of children and youth that are an absolute prerequisite to success in any academic endeavor. And we've seen little, if any, efforts to promote or support programs that will ensure that our public school students have the thinking skills--including analysis, synthesis, and problem solving--and the group process skills--including collaboration, communication, and negotiation--that will be necessary to succeed in the next economy.

For the past seven years, federal education programs have been like Lewis Carroll's Alice in Wonderland: running as fast as they can just to stand still. For the past seven years, Congress has stood up to the President as he attempted to dismantle the U.S. Department of Education, abandon federal programs for vocational education, impact aid, and postsecondary student assistance, and make deep cuts across the board in programs for disadvantaged, handicapped, and non-English speaking students.

We recognize that this Subcommittee has shown real leadership in education because its members recognize the important role education plays in our national life. Nevertheless, the prevailing attitude has been that education is a state and local responsibility. And yet, the growing number of students in our nation's public schools who are neglected, alienated, undervalued are the very ones our nation will need to drive the future economy with its emphasis on effective use of advanced technology, information, service, and adaptability. They are the ones who will be responsible for sustaining our democratic traditions and for carrying on our institutions and our national ideals.

Of the 40 million students currently enrolled in public elementary and secondary schools, one in two has a mother in the labor force, one in four is poor, one in five is at risk of becoming a teen parent, one in six has no health insurance, one in seven is at risk of dropping out of school, one in eight has limited proficiency in English, one in 10 is physically or mentally handicapped.

And yet, despite the important contributions federal education programs have made, there are still far too many students who are eligible for, but not now served in, federal education programs. Only about 40 percent of the disadvantaged students eligible for Chapter 1 compensatory education services were served in FY87. Only about one-tenth of the students eligible for federal bilingual education programs were served in FY87. Congress provided about seven percent of the cost of programs for the handicapped, less than the 12 percent provided when P.L.94-142 was enacted and far short of the 40 percent Congress intended to provide when these programs were created.

NEA is not alone in its call for full funding of federal education programs. The Committee for Economic Development recently called for a major investment in education:

> An early and sustained intervention in the lives of disadvantaged children both in school and out is our only hope for breaking the cycle of disaffection and despair....Because Chapter 1 remedial reading and mathematics programs and Head Start programs have had demonstrable success in helping narrow the gap in achievement between disadvantaged and non-disadvantaged students, we urge that Federal funding for these programs be brought up to levels sufficient to reach all eligible children.

To carry out that recommendation alone, which NEA endorses, would require an increase of more than $12 billion over FY88 levels.

These are national needs, national priorities. There must be a comprehensive range of programs to meet those needs. Henceforth, our national education policy must be "We care, and we will do everything in our power to help."

It has often been said that you can't solve problems by throwing money at them. We're not asking you to throw money. We're asking you to make a conscious, deliberate, and wise investment in our nation's human resources. We're asking you to provide support that is broad enough to reach the entire spectrum of our nation's population and deep enough to make a significant difference in their lives.

The omnibus elementary and secondary education reauthorization bill, on which Congress recently completed action, will extend and enhance a broad range of federal education programs. NEA strongly supported this measure from the very beginning. But by itself, it is only a first step. Just as each one of those programs was designed to overcome inequities of resources or abilities, each deserves funds sufficient to meet its goals. The programs reauthorized in H.R. 5 are the cornerstone of federal elementary and secondary education policy. But since learning does not begin in kindergarten or end at high school graduation, support for education should extend before and beyond these years.

Congress must support programs that help ensure that children are physically, intellectually, and developmentally ready for school, including nutrition, health care, early childhood and child care programs such as Head Start, and education for the handicapped. Congress must support programs to help special needs students, including Chapter 1 compensatory education for disadvantaged students, bilingual education, Indian education, education for the handicapped, immigrant and refugee education, and others. Congress must support programs that help school districts provide quality education, including all categories of Impact Aid, Chapter 2 block grants, and concentration grants. Congress must support programs that help teachers and other education employees improve their teaching skills, including math and science education and Professional Development Resource Centers. Congress must help promote full integration in our schools and in our society through Magnet Schools programs and support for the Office for Civil Rights. Congress must help identify national priorities in education and develop programs to promote those priorities through support for education research and development.

Congress must support programs that give every qualified individual an opportunity to pursue learning opportunities beyond high school, including postsecondary student assistance, adult vocational programs, job training programs, adult literacy, and adult education programs. Congress must support programs that strengthen educational institutions, including libraries, colleges, and universities. Congress must support programs for children and youth that give them a second chance, such as juvenile justice programs, programs for runaway and homeless youth, drug abuse prevention and treatment, child abuse prevention and treatment, and dropout prevention and reentry programs. Congress must support programs that enhance educational opportunities beyond the school setting, including public television. And Congress must support programs that protect the health and safety of public school students.

Do not ask us to choose among these programs. They are all important; they are all essential. We may be accused of wanting it all, but that is a reflection of the will of the American people. The American people, now and always, want it all. They want a nation of strong, determined people--people who have the skills to continue America's world prominence. They want a nation secure from external attack or internal decline. They want social justice, economic vitality, and a democratic form of government. They want to continue as a nation united in its commitment to the rights of individuals. All of these things emanate from our educational system, taken in its broadest interpretation. If we invest in our nation's people, we can have it all. If we ignore any segment of our nation's population, we do so at our peril.

In shaping an FY89 Labor-HHS-Education Appropriation, Congress must restore funds lost in education programs as a result of last year's conference committee action, provide at least sufficient funds to keep pace with inflation for all education programs, and provide additional funding--as assumed in the House and Senate-passed versions of the FY89 Budget Resolution--to restore education services lost over the past seven years as a result of budget cuts, inflation erosion, and increased needs.

The Congress has the opportunity to help shape the future. Do not let that opportunity pass.

Thank you.

Senator **Weicker**. Thank you very much, Mr. Timmons.

I think we meet, if I am not mistaken, this afternoon, do we not, 2 o'clock this afternoon on the allocations, and I have been led to believe that we might be adjusting. It will certainly be raised.

I think that I have said this in all the years I have been here. I have said, you know, this matter of education is not a Republican or Democratic thing, and I think the Democrats have found to their embarrassment that these levels are below the President's, who I have been fighting for 5 years. Now they are getting into the act. We need more money. We do not need the President and the Democrats agreeing on lower education sums, I will put it that way.

Thank you very much.

Mr. **Timmons**. Thank you, sir. We are grateful for your help.

Senator **Weicker**. Before I move on for the last time, is Mr. Humphrey here representing the American Federation of Teachers?

[No response.]

STATEMENT OF JAMES R. OGLESBY, PRESIDENT-ELECT, NATIONAL SCHOOL BOARDS ASSOCIATION

Senator **Weicker**. We will go to our last witness, Mr. James Oglesby, president-elect, National School Boards Association

Mr. Oglesby, nice to have you here.

Mr. **Oglesby**. Thank you, sir.

Senator Weicker, it is good to see you. My name is Jim Oglesby. I am president-elect of the National School Boards Association. Leonard Rovins from your State is our president this year. He could not be here, and I am presenting the testimony on his behalf.

I would like to just supplement the remarks that you have in full detail. We appreciate the support that we received last year from the Federal Government for the education funding. This year this budget that has been presented by the president does not nearly meet the costs and the needs of education. On April 15 I spent the day with USA Today reading the proposals of 200 academic scholars. You came in on May 16 and gave a strong presentation to those students about your support and what they need to do in order to make their contribution to society.

There was enough brain power in that room, I think, as you know, you could feel the magnetism of the people that were there and the students that were there, and I think those students are going to make a contribution.

I think you challenged them, and I believe that that challenge will not go unwarranted. I believe that they will do whatever they can. But I would like to go back and tell them that this Congress is doing whatever it can to fund not only their future education but the education of their children so that they will be able to receive the kind of education and that their children will be able to receive the kind of education that has allowed them to be as successful as they have in their academic programs.

We also realize that there are a number of at risk youths in this country, and we want to address the needs of those at risk youth, and in order to do that, we are going to have to have some additional support from the Federal Government.

I realize that the compromise is that you have to make some reductions, but I want to go on record as saying the National School Boards Association wants the Congress to know that the Federal Government has a role to the education of the kids in this country. More so, we also urge the fulfillment of the commitment made to the Hawkins-Stafford amendment to provide full funding for chapter 1. We also want the full funding support for handicapped education that has never been up to the commitment, as you know.

We have tried to, at the local level, provide a basic education with the mandates that have been provided by the Federal Government, and we are going to continue to do the best we can with the resources that are available, but I think you should also know that the States are suffering from a shortfall of revenues which will not allow them to continue to provide that quality education to the broad range of students that we are trying to serve without some additional help.

NSBA believes that each one of the initiatives that are there deserve some special consideration by this Congress. We also urge you to reject the President's request to eliminate impact aid B and also provide full funding of the $735 million under H.R. 5.

PREPARED STATEMENT

Last, I would like to say to you that tomorrow night I will give the graduation speech at one of our high schools where 460 students are going to graduate and either go to college or go out into the world of work. I would like to go back and tell those students that the Congress of the United States is in support of their education in the future and their kids' education in the future.

Thank you for your time, sir.

[The statement follows:]

STATEMENT OF JAMES R. OGLESBY

I. INTRODUCTION

I am James R. Oglesby, President-Elect of the National School Boards Association, and a local school board member from Columbia, Missouri. I appreciate this opportunity to testify before this Appropriations Subcommittee on behalf of the 95,000 local school board members.

II. OVERVIEW OF FY 89 FUNDING REQUESTS

NSBA commends the Subcommittee for the significant increases appropriated in Fiscal Year 1988 for the major federal education programs like Chapter 1 and the Education of All Handicapped Act. These programs are a necessary investment in the future well-being of our society and not a cost to be cut to reduce the deficit.

The President's budget request for Fiscal Year 1989 calls for a modest 3.1 percent increase for education. While an improvement after years of proposals for massive cuts, the President's budget does not keep pace with the costs of current vital educational services.

More disturbing, the President's budget does not look to the future. It does little to address the increasing needs of a growing disadvantaged school population. And it makes no new investments to improve our competitiveness in the world economy.

III. "AT-RISK" YOUTH AND THE NATIONAL ECONOMY

Each year we find a growing proportion of students who are "at-risk" of school failure. More students come to school with serious impediments to learning including poverty, physical or mental handicaps, and limited ability to speak English. A full twenty-five percent of our students are not expected to finish high school.

Soon these children will make up one third of the united states workforce competing in a world marketplace that puts a premium on increased productivity. Yet without a solid foundation in literacy, computation, and critical thinking skills, these students will be unable to perform up to the standards our economy will demand.

Fortunately, our federal education programs -- especially those recently reauthorized in H.R. 5 -- can go a long way to serve "at-risk" youth.

IV. EDUCATING FOR THE 21ST CENTURY: SPECIFIC PROGRAM RECOMMENDATIONS

NSBA urges the Committee to consider several priorities for new funding that are within the assumptions of the FY 1989 House Budget Resolution and address the needs of "at-risk" students: Chapter 1, handicapped education, and new H.R. 5 inititatives.

A. PRIORITY PROGRAMS FOR "AT-RISK" YOUTH

1. CHAPTER 1

Chapter 1 has proven itself effective in increasing educational achievement among disadvantaged students. H.R. 5, the new Hawkins-Stafford School Improvement Amendments, commits **Congress to providing increases of $500 million a year above inflation until all eligible disadvantaged students are served.**

NSBA strongly urges the Committee to fulfill this commitment particularly since, this year, the new amendments target $400 million of this increase in concentration grants to those students most in need. This increase will expand reading and math services to at least 750,000 additional students.

2. HANDICAPPED EDUCATION

P.L. 94-142, the Education of All Handicapped Children Act, requires local schools to provide special education services to over 4 million students with learning disabilities and physical, mental, and emotional handicaps.

While the Act authorizes the federal government to cover 40 percent of the excess costs of this federal mandate, its share now stands at less than nine percent.

In 1986, Congress expanded the local responsibility for serving handicapped youngsters by creating the **preschool incentive grant** program. This program requires participating states to serve all handicapped children ages 3-5 years old by school year 1990-91.

Current figures on the number of children actually participating in this program show that the original projections were seriously underestimated. As a result, the program will accumulate a large funding shortfall by FY 89 resulting in corresponding reductions in per-child grants unless appropriations are significantly increased.

NSBA strongly recommends that the committee appropriate at least $200 million above inflation to increase the federal share of the basic grant program, and to fully fund the preschool handicapped program.

B. H.R. 5 INITIATIVES FOR "AT-RISK" YOUTH

The Hawkins-Stafford amendments also authorize several new or expanded programs to serve "at-risk" students.

-- The **secondary school basic skills and dropout prevention programs** which fund projects for at-risk high school students.

-- The expanded **Magnet Schools Assistance Program** which enables many more school districts to establish quality integrated magnet schools.

-- The new **Even Start Program** which attacks the problem of illiteracy among poor children and their parents.

NSBA believes each of these promising initiatives deserves special consideration by the Committee for new funds in FY 1989.

C. OTHER PROGRAMS OF SPECIAL IMPORTANCE

NSBA also recommends that the Committee restore the cuts made in vocational education basic grants and the Chapter 2 Block Grants in FY 88.

We also urge the Committee to reject the President's request to eliminate Impact aid "b" funding and instead, provide the full $735 million authorized under H.R. 5 for school districts serving federally connected students.

NSBA requests adequate funding for several important programs related to science and technology. The new **Star Schools Program** shows great promise of improving math, science and foreign language education in rural schools through satellite technology.

The **Math/Science Teacher Training Program** deserves increased funding especially since the Hawkins-Stafford amendments greatly improve the allocation of resources to local school districts.

Finally, if H.R. 3, The Trade Bill, is enacted, NSBA also requests initial funding for the **Technology Transfer Training Act** which would transfer training technology developed in federal activities to local schools.

V. CONCLUSION

As locally elected officials, we urge the committee to make a major investment in our young people's education and in the future well-being of America.

Thank you for the opportunity to testify before the Committee today.

Senator **Weicker**. Mr. Oglesby, thank you very much for your testimony.

I think you can go back and say that the Congress feels that we are 100 percent behind the cause of education, but what the Congress has to do now is to say that we are willing to go ahead and put our money where our mouth is.

Mr. **Oglesby**. That is correct.

Senator **Weicker**. You know, you are absolutely right. You cite Public Law 94-142, a 40-percent commitment? We have never gone over 8 percent.

Mr. **Oglesby**. Never.

Senator **Weicker**. And the other matters that you raise here, chapter 1, and I might add, all the additional educational burdens that are coming upon us, drugs, AIDS, I don't care, that is all going into the education, has to go into the education area. I hear a lot of talk, but you know as well as I do that the only thing that makes any difference is that the money is there.

Mr. **Oglesby**. As part of my speech to the students tomorrow night, the problems in the 1940's, children chewing gum, wearing the wrong clothes, throwing paper in the trash can, getting out of line in school; the problems today, drug education, education of the handicapped, providing some safety for the kids, security to keep from becoming raped or robbed or whatever in school, there is a lot of money that is going into education that is not going directly into the educational program. Those of us like myself that are elected local school board members where if anything goes wrong that constituent can pick up that phone, and they can get me right on the phone that night to complain about it, then I think that I should be able to come to this table and say that we need some support for those programs so we don't have to make decisions as to whether or not we pay our utility bill or whether or not we provide additional support for a student that needs some in-home treatment.

Senator **Weicker**. Well said. Well said, and I thank you very much.

Mr. **Oglesby**. Thank you.

CONCLUSION OF HEARINGS

Senator **Weicker**. This concludes the fiscal year 1989 hearings. We have had 14 hearings with department and agency administrators responsible for $129 billion of Federal spending, and we have now had nine full sessions covering 225 public witnesses.

I think this is an important part of the process. I want to thank each one of the public witnesses that has appeared.

The subcommittee will now stand in recess until the call of the Chair.

[Whereupon, at 11:15 a.m., Thursday, June 9, the hearings were concluded, and the subcommittee was recessed subject to the call of the Chair.]

Material Submitted Subsequent to Conclusion of Hearings

[CLERK'S NOTE.—The following statements and letters were received subsequent to the conclusion of the hearings, and will be inserted in the record at this point.]

DEPARTMENT OF LABOR

STATEMENT OF THE SOUTHERN WILLAMETTE PRIVATE INDUSTRY COUNCIL

The Southern Willamette Private Industry Council which serves Lane County, Oregon, received the 1987 National Alliance of Business Distinguished Performance Award for Dislocated Worker Programs. In the beginning, the Program was faced with providing services to literally hundreds of laid-off woods products workers. As more and more mills shut down and those remaining automated to increase productivity, there was an economic ripple effect which reached almost every sector of the local labor market.

This Dislocated Worker Program was so successful in providing retraining and reemployment services to Lane County residents because of the interaction of two unique features: 1) the high level of genuine cooperation among sponsoring organizations, and 2) the Dislocated Worker Program philosophy.

The first key component of the Dislocated Worker Program's success is the strong link forged among the cooperating partners which include:

- Southern Willamette Private Industry Council
- Lane Community College
- State Employment Division
- Labor Unions
- Business and Industry

A firm commitment to providing reemployment assistance to Lane County's dislocated workers has guided their interactions and has allowed them to create innovative and effective relationships. They have ignored turf issues and eliminated bureaucracy in order to best serve these workers.

Each partner plays an essential role in the delivery of services to laid off workers.

- **The Southern Willamette Private Industry Council** functions as the umbrella organization and subcontracts with Lane Community College to operate the Dislocated Worker Program.

- **Lane Community College** provides quality vocational training opportunities, career/life planning, job search training that also bolsters self-esteem, and support services.

- **The State Employment Division** offices conduct local state employment service recruitment and eligibility in addition to the dispersal of unemployment insurance benefits to dislocated workers.

- **The Labor Unions** sit on a special advisory board to assist with program operations.

- **Business and Industry** participate in Private Industry Council advisory committees. They assist with vocational training by using their facilities and employees, and by hiring qualified applicants when job openings occur in their businesses.

This well-coordinated alliance permits rapid response to plant closures, vocational training based on the needs of the local labor market, and daily support both monetary and emotional for dislocated workers as they begin to put their lives back together.

The second key component of this Dislocated Worker Program's success is the philosophy that all workers will become re-employed. An independent study commission by the Department of Labor identified this philosophy as being unique among programs nationwide. The Program emphasizes life and career planning, stressing that there is a "right" job for everyone. Dislocated Workers are encouraged to look at their loss of work and entry into the program as an opportunity to discover new directions. The philosophy is based on the premise that only by getting to know oneself can a person create a satisfying life and select the best occupation for their individual needs.

This philosophy is transmitted from the program staff to the participants throughout the time they are in the program. Genuine concern and encouragement during the course of their job search is a critical factor of the project's success. The Dislocated Worker Program staff as a team, and individually, are committed to helping each participant meet their goal. Weekly staff meetings and frequent informal sessions provide updates on the status of individual participants and the program as a whole. Problems and concerns are discussed openly and action plans developed. All participants receive well-focused, individual attention in support of the Program's philosophy.

The Southern Willamette Private Industry Council's Dislocated Worker Program in Lane County, Oregon deserves its national recognition. It exemplifies what can occur when organizations cooperate and people really care about the future and lives of dislocated workers in American society.

STATEMENT OF THE AMERICAN FEDERATION OF LABOR-CONGRESS OF INDUSTRIAL ORGANIZATIONS

The American Federation of Labor-Congress of Industrial Organizations (AFL-CIO), the Chamber of Commerce of the United States, and the Interstate Conference of Employment Security Agencies (ICESA) are pleased to submit this statement to the Subcommittee on Labor, HHS and Education of the Committee on Appropriations of the United States Senate.

Over the last six budget years, the employment security system has suffered severe budget reductions, which have resulted in fewer locations where unemployment claims can be filed and employment services obtained, as well as a reduction in the types of employment services offered. Employers, workers and administrators are all concerned about this decline in services.

As you know, federal unemployment taxes are imposed on employers to pay for the normal administration of unemployment insurance and employment service programs. These are not general revenue funds and their use is legislatively restricted to the purpose for which they were imposed. In FY 1988, the Department of Labor estimates that $3.51 billion will be collected under the Federal Unemployment Tax Act (FUTA) for employment security administration, while expenditures for administration are estimated at $2.74 billion; in FY 1989 the President's request for employment security totals $2.72 billion, about $1 billion less than estimated FUTA revenues of $3.75 billion. It is difficult for employers, workers and administrators to understand why the employment security system must face continued reductions when the federal government expects to collect $1 billion more in federal unemployment taxes in FY 1989 than the Administration plans to spend for employment security programs.

There will always be disagreements between the states and the Secretary of Labor about the amount of funds necessary to administer properly and efficiently the unemployment compensation laws and provide public employment services; however, the level of federal funds has reached the point that many states have been forced to supplement federal funds for UI, ES and labor market information with state funds. Some states have appropriated state general funds; a growing number are enacting state payroll taxes for UI and ES administration. Employers and, ultimately the public, are paying twice for employment security services in these states.

ICESA recently surveyed states to determine how many are using state funds to supplement federal funds for employment security programs. The survey showed that 29 states spent $85.3 million in state funds for employment security programs in FY 1987 and expect to spend $117.5 million this fiscal year. This is a very recent phenomenon in the 53-year history of this country's employment security system. The taxing authority and responsibility for funding rest at the federal level. Unless these arrangements are altered, states should not be forced to raise revenues in order to provide services for which the federal government has already imposed a payroll tax.

States know that they are, in effect, letting the federal government off the hook by providing state funds to keep programs operating at a level that meets minimum state needs, but the alternative is to operate an employment security system that is simply not acceptable to the employers and workers of the state.

The following discussion describes in more detail the financial situation of employment security programs.

Employment Service (ES)

Over the past six years ES staff has been reduced to approximately 17,000 from the 1981 level of approximately 32,000. The number of full-time counselors has been reduced nearly 75%; seven states report that they have no qualified counselors on staff. The number of individuals counseled has dropped 45% from FY 1981. The testing program has also been adversely affected. In addition, employer services components have been either eliminated or significantly reduced in all states.

In recent years, the system has used available funds to stabilize staff levels and local offices to the extent possible. Therefore, the system has not had funds to invest in automation. Currently, 50% of all local offices have no automated services; 78% of all local offices are not automated in employer services; and, automated job matching is used in fewer locations than it was five years ago.

In order to stabilize the ES system and avoid further contractions in services, we request that you provide funding for

FY 1989 at the FY 1988 level, plus inflation. In addition, we request that funds be provided specifically for automation of ES activities. Congress has recognized this need by authorizing $50 million for ES automation as part of H.R. 3, the omnibus trade bill. While the need is great, a small amount provided each year, beginning in FY 1989, would begin to address ES automation needs.

Unemployment Insurance (UI)

Over the period from 1981 to the present, staffing for unemployment insurance activities has declined from about 54,000 in 1981 to the current level of about 40,000. Most of these reductions are related to lower levels of unemployment and fewer claims for UI benefits; however, these reductions have still been difficult to manage. The reduction in ES staff over the past six years has also had an impact on the UI system because the two programs often share offices, equipment and other overhead costs. As ES funds have been reduced, the UI program has had to pay for a larger portion of these shared costs. As you know, there have been continual shortages of these "non-personal services" funds, which this Subcommittee has addressed several times in recent years.

The President's request for UI operations in FY 1989 would maintain staff at about the current level, but would reduce the "base" or permanent staff level by about 10%, shifting those to the "contingency" or temporary staff category. While claims for unemployment benefits are now at a very low level, we are very concerned about maintaining trained staff to respond adequately when unemployment claims increase.

The various formulas for funding UI operations should be examined and revised to provide guaranteed minimum levels to states and to make the distribution of funds for overhead costs less directly related to staff levels.

Labor Market Information

Labor market information is a vital component of the employment security system. It provides data and management information to assist UI/ES operations and supports policymakers in the evaluation of labor market conditions. This "economic intelligence" system, upon which so many critical employment/training decisions are made, needs to be strengthened.

Funds for gathering key information have been curtailed over the last several years--resulting in reduced unemployment data reliability for several cities, less occupational detail data, current employment data cutbacks, and other related data evaporation. Adding to this problem is the lack of technical assistance and coordination from the Department of Labor for the maintenance of a comprehensive state/local labor market information system.

For FY 1989, we ask that you restore $2.6 million in cuts made in FY 1988 by the Bureau of Labor Statistics to the following key statistical programs: Occupational Employment Statistics; Current Employment Statistics; and Current Population Survey. It is also requested that funding be raised for the Job Training Partnership Act (JTPA) Title IV D labor market information line item, from the Administration's request of $4.4 million to $7.5 million in order to produce adequate occupational data needed in planning employment/training programs.

STATEMENT OF THE AMERICAN INDIAN BUSINESS DEVELOPMENT CONSORTIUM

Mr. Chairman, we appreciate the opportunity to submit this written testimony on behalf of the American Indian Business Development Consortium.

BACKGROUND

In Michigan the Tribal leaders met among themselves in 1986 to discuss strategies for Indian economic development. They agreed to approach the Michigan Department of Commerce for assistance. On March 26, 1986 16 key Indian leaders who officially represented all 10 Michigan Indian Tribes and the six urban Indian centers met with the Department of Commerce and the Michigan Commission on Indian Affairs.

In May of 1986, as a result of the State/Tribal meetings, an interim board was created to develop the ground work for a statewide Indian Community Growth Alliance (CGA).

In late 1986, efforts were begun to form the American Indian Business Development Consortium (AIBDC). Many Tribes and organizations were involved in the formation of AIBDC and the by-laws were formally adopted on Friday, January 23, 1987. The AIBDC Board was composed of 9 members: 3 tribal representatives, 3 urban organization representatives, 2 private business representatives, and 1 representative from the Michigan Commission on Indian Affairs.

FY 1988 Congressional Funding

The newly formed AIBDC Board also moved at the January 23 meeting to take the initial steps necessary to create an Indian Community Growth Alliance (CGA), and as a result the AIBDC is now an official Indian Community Growth Alliance in Michigan. This was an extremely important step, since it allowed AIBDC to create an Area Development Office (ADO) and a Small Business Center (SEC) as part of the CGA Program. The ADO office is housed in Sault Ste Marie, while the SBC maintains offices in Lansing. These offices have been approved by the Michigan Department of

Commerce and are currently providing services to Michigan Indian Tribes, organizations, and individuals. The staff provides technical assistance in the areas of business plans, marketing plans, management techniques, financial packaging, accounting methods, site selection and legal structure.

The AIBDC Board also initiated a request for Congressional appropriations in February of 1987. The AIBDC was responsible basis for seeking Congressional funds for Indian economic development in Michigan. On March 5, 1987, testimony by AIBDC Board was presented to the Subcommittee for Interior and Related Agencies of the House Committee on Appropriations.

As a result of the request and the strength of the Michigan Indian Seven Point Plan an appropriation of $425,000.00 was added to the Bureau of Indian Affairs FY 1989 budget for AIBDC. These funds are being used to develop an overall State of Michigan/Indian Economic Development Strategic Plan, to create viable businesses, joint venture opportunities and employment opportunities. In combination these would blend state, federal, and private sector capital to create the foundation for self-sustaining Indian economies.

AIBDC is now moving to implement the next phase of the Michigan Indian Seven Point Plan. AIBDC and the Michigan Department of Commerce have proposed the development of an Indian Business Development Corporation (BIDCO). The Michigan Indian BIDCO would make necessary capital available to Michigan Indians to stimulate Indian business development.

The BIDCO would be created through blending $750,000 from the State of Michigan Strategic Fund, federal dollars, and private sector capital to create a 2 1/2 million dollar loan fund.. The Michigan Indian BIDCO would be structured as a profit arm to the non-profit American Indian Business Development Consortium.

FY 1989 Congressional Funding

a. Tribal

In March of this year, AIBDC requested a $500,000.00 appropriation from the BIA to form the BIDCO and to provide loans to Indian Tribes.

b. Urban

In addition AIBDC requests that your subcommittee recommend that $500,000 in FY 1989 existing ANA funds be earmarked for AIBDC to provide BIDCO loans to urban Indians. The 1980 Census shows that 90% of the Michigan Indians live off the reservations, because the Indian Removal Act of 1830 extinguished title to land for the majority of Michigan Indian Tribes. There now exists a great need for development of business opportunities for Michigan's 61,000 plus Indians living off-reservation.

Funds earmarked for off-reservation BIDCO loans will create joint venture opportunities for urban centers with private sector Indian entrepreneurs. Private sector Indian business persons because of their experience, hold the greatest single untapped resource available to tribes and non-profit Indian economic development. Through tapping into the experience and expansion of already developed Indian businesse, Michigan Indians intend to side step the high failure rate of Indian business start-ups.

Conclusion

At the present time, a range of services are being provided by AIBDC to Indian Tribes, organizations and individuals. These services include technical assistance which can short circuit some of the pitfalls associated with Indian economic development ventures in the past. Presently Tribes and Indian organizations have knowledge of a variety of possible business startups in their area. BIDCO will allow access to capital to create, or expand business for Michigan Indians.

It will be important to promote urban Indian organizations and Tribal joint venturing through AIBDC services to maximize economic development potential. The development of Tribal business joint ventures with urban Indian centers (and the Indian and non-Indian private sector) presents a new avenue for business development in Michigan.

STATEMENT OF BILL STEINBERG, CHAIRMAN, LOS ANGELES COUNTY REFUGEE FORUM

My name is Bill Steinberg. I am here representing Lutheran Social Services of Southern California. Lutheran Social Services, like the other religiously based organizations, has been involved in assisting immigrants and refugees coming to our shores since before the founding of this nation. For over two centuries, Lutherans and other religious bodies have helped their own. This tradition continued until the nineteen-forties when the major dislocations that occurred during and after the Second World War created problems of a magnitude that the social service arms of American churches and synagogues could no longer handle. The various organizations looked to their government for assistance.

After the war, the failed revolutions against communism in Eastern Europe forced additional thousands to seek protection on our shores. This was followed by the fall of the Saigon government in 1975. With the arrival of the huge number of people fleeing the communists in Indochina, it became painfully clear that the tradition of privately financed and privately operated resettlement could no longer be the sole model.

The private resettlement agencies turned again to their government for assistance - and a wise partnership was created. The traditional resettlement agencies would continue to handle the job of resettlement, under guidelines established by Congress. The states would administer the programs within their boundaries - and the Federal Government would set the limits of resettlement, establish admission ceilings, create the guidelines, and fund the cost of resettling the refugees for their first 36 months in the U.S.

This partnership held fairly strongly through the first years after Congress passed the landmark Refugee Act of 1980. In recent years however, there has been a steady erosion of the Federal government's commitment to this program. The period of federal reimbursement to states and counties has been continuously decreased. As others here have testified, the Administration is now proposing cuts in its responsibility that will make a dignified and honorable resettlement of these proud but needy people virtually impossible.

Under the proposed cuts, there will not be enough resources for even minimal English instruction. Vital health screening programs will be decimated, programs geared to job training and job placement will be cut so much that only a fraction of the needy will be assisted. In short, some fortunate refugees may be admitted, but then all assistance and humanitarian concern will abruptly cease.

We live in an era of major budget deficits. We cannot provide everything that the less fortunate need. Still, it is very hard to believe that we cannot provide the minimum that we demand for our own childrden - English instruction, health care and assistance in finding their first jobs.

I can assure you, Ladies and Gentlemen, that the private sector remains fully committed to helping the needy in our society. However, we are concerned and saddened when our leaders seem willing to walk away from a responsibility that goes to the very spiritual heart and foundation of this nation. Please don't let this happen.

DEPARTMENT OF EDUCATION

STATEMENT OF DAVID K. KARNES

MR. KARNES: MR. CHAIRMAN, I AM PLEASED TO HAVE THE OPPORTUNITY TO TESTIFY BEFORE THE SENATE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES ON BEHALF OF 15 NEBRASKA SCHOOL DISTRICTS THAT DEPEND TREMENDOUSLY ON IMPACT AID FUNDING. THE IMPORTANCE OF IMPACT AID TO MY STATE OF NEBRASKA AS WELL AS THE REST OF THE COUNTRY CANNOT BE OVERSTATED. FOR INSTANCE, BELLEVUE SCHOOL DISTRICT, THE LARGEST RECIPIENT OF IMPACT AID FUNDS IN NEBRASKA, DERIVES ONE-THIRD OF THEIR REVENUES FROM THE IMPACT AID PROGRAM.

IN 1950, CONGRESS RECOGNIZED THE NEED FOR A FEDERAL COMMITMENT TO LOCAL EDUCATIONAL AGENCIES WHO SERVE FEDERALLY CONNECTED CHILDREN; I.E., "A" STUDENTS, DEPENDENTS OF MILITARY PERSONNEL RESIDING ON BASE, AND "B" STUDENTS, DEPENDENTS OF MILITARY PERSONNEL RESIDING OFF BASE. IT IS VITAL TO THE WELL-BEING OF OUR EDUCATION SYSTEM AND THE DEVELOPMENT OF THE MINDS OF OUR CHILDREN THAT CONGRESS CONTINUE TO PROVIDE FINANCIAL ASSISTANCE TO FEDERALLY IMPACTED SCHOOL DISTRICTS.

LEGISLATION WAS APPROVED THIS PAST APRIL THAT MAINTAINED THE IMPACT AID PROGRAM THROUGH FISCAL YEAR 1993. I SUPPORTED THIS

REAUTHORIZATION AND I BELIEVE THAT THE FEDERAL GOVERNMENT MUST CONTINUE TO RECOGNIZE ITS RESPONSIBILITY TO OUR NATION'S SYSTEM OF PUBLIC EDUCATION. OUR OBJECTIVE IN CONGRESS MUST BE TO FUND COMPLETELY THIS EXTREMELY IMPORTANT PROGRAM, DESPITE RECOMMENDATIONS BY THE ADMINISTRATION TO CUT BACK OVERALL FUNDING AND ELIMINATE CATEGORY "B" FUNDING. CONGRESS MUST RECOGNIZE THAT IMPACT AID IS A NECESSITY, NOT A SUPPLEMENTAL PAYMENT.

MR. CHAIRMAN, I REALIZE THAT CONGRESS IS STRUGGLING TO REDUCE THE FEDERAL DEFICIT. HOWEVER, WE CANNOT ACHIEVE THIS GOAL AT THE EXPENSE OF OUR CHILDREN. I STRONGLY URGE A

FUNDING LEVEL AS AUTHORIZED IN PUBLIC LAW 100-297.

THE INVESTMENT OUR NATION MAKES IN EDUCATION TODAY, WILL DIRECTLY AFFECT OUR FUTURE POSITION IN THE WORLD ECONOMY. ON MATTERS OF EDUCATION WE MUST RECOGNIZE THAT AMERICA'S COMPETITIVE POSITION IN THIS EVER-CHANGING WORLD IS BASED ON THE SKILLS AND KNOWLEDGE OF OUR CITIZENS WHICH COMES NOT BY CHANCE, BUT THROUGH EDUCATION.

STATEMENT OF RALPH W. ADAMS, CHANCELLOR, TROY STATE UNIVERSITY, TROY, AL

The purpose of this testimony is to present information regarding the funding inequities four-year institutions are facing in the Strengthening Institutions Program authorized by Part A of Title III of the Higher Education Act (HEA) of 1965 as amended. These funding inequities are caused by Section 360 (c) and (d) which was added to the Act as an amendment in 1986. We propose to prove that as a result of adding Section 360 (c) and (d) to the HEA, the original intent and purpose of the 1965 Act is being abrogated, worthy students will be denied essential programs, and outstanding university programs now operational are threatened with a severe reduction in quality, if not total program extinction.

The purpose of the Strengthening Institutions Program, Part A of Title III is "to help eligible colleges and universities to solve problems that threaten their ability to survive and to stabilize their management and fiscal operations so that they may achieve self-sufficiency" and "to assist such institutions in equalizing educational opportunity through a program of Federal assistance." The purpose is to help eligible colleges and universities, but in 1986, Section 360 (c) which reserved $51.4 million for junior or community colleges was added to the Act by amendment. The result of this amendment has been elimination of four-year institutions from receiving any new Title IIIA grants in FY 88, and four-year institutions who have non-competing continuation (NCC) grants are facing reductions of as much as forty percent (40%) in their FY 88 allocations. By eliminating from contention only four-year institutions which have been deemed eligible and by reducing in a draconian manner only those NCC grants allocated to four-year institutions, Section 360 (c) and (d) not only discriminates against this class of institutions but also abrogates the original intent and purpose of the Higher Education Act. The Strengthening Institutions Program will no longer provide equitable help to all eligible colleges and universities; it will provide help to two-year institutions only. Thus, the unstated premise of this amendment is that only the junior and community colleges have the serious problems addressed by the Higher Education Act of 1965. The fallacy of this premise is self evident.

The need for Title III, Part A funds and the injustice promulgated by the elimination of these funds to four-year institutions become evident when the regions and students served by a typical four-year, Title-IIIA-funded institution are examined. Located in a rural community of southeastern Alabama, Troy State University attracts a large part of its student body of 3,589 (fall quarter, 1987) from the predominantly agrarian area of south Alabama, south Georgia, and northwestern Florida. Fifty-three percent of this student population is female and 17.5% is black. The University's primary drawing area, by most accepted definitions, qualifies as an economically disadvantaged, poverty-ridden region. In Pike County where the University is located, a Donnelley Demographics Report of February, 1988, showed a per capita annual income of $4,701 with fifty-one percent of the households with incomes less than $10,000. According to the "1987 Survey of Buying Power Data Service" of the Sales & Marketing Management Magazine, the mean per capita income of the southeastern Alabama area served by Troy State University was $7,448 for 19 counties in this area. These income levels are well below the 1987 poverty threshold of $11,612 for a family of four (Poverty, Income, and Wealth Branch, Census Bureau, 1988). The population of the Pike County area is 36% non-white. Many Troy State students are first generation college students whose parents may lack even a high school education. Such economically and educationally disadvantaged students normally experience high attrition rates.

Through the efforts of the programs funded under Title III, Part A, Troy State University has developed some of the best programs in the nation for educationally disadvantaged students. Troy State

University's developmental education programs have been hailed as outstanding by authorities such as Dr. John Roueche of the University of Texas. The University's most recent student tracking information from winter quarter, 1988, showed that all students who successfully completed the developmental writing and science programs passed the first degree-credit English or science course which they attempted. Seventy-three percent of the students who took preparatory mathematics passed college algebra, and the natural science support laboratory has logged over 50,000 visits since March, 1982.

In addition to assisting students in basic skills coursework, the University also provides students and faculty with computer services and training, assists students in their career exploration efforts, coordinates a writing-across-the-curriculum program to aid students in their thinking and content-area writing, and develops learning programs by using interactive video technology. All of these highly successful programs have been developed with Title III, Part A assistance.

To reduce Title IIIA funds to four-year institutions and to eliminate universities such as Troy State University from competition for future funds may mean not only the end to development of programs to assist thousands of educationally and economically disadvantaged students but also the end of ongoing research which has helped the University identify the best methods of assisting the educationally disadvantaged student. To eliminate from Title IIIA an eligible four-year institution that consistently develops outstanding programs to alleviate the very problems addressed by the HEA for one reason only--that the institution happens to be a four-year institution--is obviously at cross-purposes with the original intent of the HEA.

We urge the Committee to increase the appropriation for Title III, Part A, the Strengthening Institutions Program to a level that would equitably fund both two-year and four-year programs, but because we can not anticipate increased appropriation for each year in the future and because the funding problems for four-year institutions originate from

Section 360 (c) and (d) of the Higher Education Act (HEA), the language of that section of the Act needs to be changed. To remedy the long-range funding problems for four-year institutions, there are several options which we support. In Section 360 (c) and (d), rather than state that an amount of money ($51.4 million) will be reserved for two-year institutions, state that a certain percentage of funds will be reserved for two-year institutions. By substituting a percentage for a dollar amount, any appropriations for Title IIIA funds would be allocated equitably and proportionally to two-year and four-year institutions. A second option is to reserve in the HEA an amount or percentage of funds for four-year institutions. A third option is to eliminate Section 360 (c) and (d) altogether from the HEA and allow two-year and four-year institutions to compete equally for any available Title III Strengthening Institutions funds.

In summary, we believe that the original intent and purpose of the Strengthening Institutions Program, Part A of Title III of the Higher Education Act of 1965, as amended, is being abrogated. No longer does the Strengthening Program equitably support eligible colleges and universities; it supports two-year institutions while four-year institutions with non-competing continuation grants face drastic reductions in funds for their programs, and all eligible four-year institutions face the prospect of not being allowed to compete for new funds now and in the future. Abrogation of the original purpose of the HEA and reduction or even elimination of outstanding programs which provide services for worthy students should be sufficient justification to change the language of the HEA so that four-year institutions may also be allowed to "solve problems that threaten their ability to survive and stabilize their management and fiscal operations so that they may achieve self-sufficiency" and be assisted in "equalizing educational opportunity through a program of Federal assistance"—the Strengthening Program of Title III of the Higher Education Act of 1965 as amended.

STATEMENT OF THE NATIONAL COUNCIL OF LA RAZA

The National Council of La Raza, one of the largest national Hispanic organizations, is pleased to submit testimony on Fiscal Year 1989 appropriations for the English Literacy Grants Program in the Adult Education Act. The Council requests that this Committee fully fund the English Literacy Grants Program at $26.3 million.

The National Council exists to improve life opportunities for Americans of Hispanic descent. It is a private, nonprofit organization which serves as an umbrella for more than 80 "affiliates" -- local Hispanic community-based organizations serving 32 states, Puerto Rico, and the District of Columbia -- and has a national network of more than 4,000 organizations and individuals. The Council has a longstanding commitment to improving the educational opportunities available to Hispanic children, youth and adults.

There is a critical need for accessible and affordable English literacy services for adults and out-of-school youth of limited English proficiency. Among the adult Hispanic population alone, there exists an egregious functional illiteracy rate.

Depending on the standard used, the Hispanic illiteracy rate is between 11.9% and 56%. Regardless of the measure employed, Hispanics have substantially higher rates of illiteracy than the White or Black populations.

By the traditional measure of literacy -- the completion of less than six years of schooling -- 11.9% of Hispanics over 25 years of age could be considered illiterate compared to 1.8% of the total non-Hispanic population in the same age group. When years of school completed are used, Hispanics are much more likely than Whites or Blacks to be classified as illiterate because the school retention and completion rates are so much lower for Hispanics. Only 50.9% of Hispanics 25 years of age and over have completed four years of high school, compared to 77.3% of the non-Hispanic population.

Based on other measures, Hispanics have much higher rates of functional illiteracy. The 1975 Adult Performance Level Study (APL) developed a standard for functional literacy which divided adult functional competency into three levels: APL 1, 2 and 3. APL 1 equaled functional illiteracy, APL 2 marginal literacy, and APL 3 meant advanced literacy. According to these standards, 56% of Hispanics were at APL 1, compared to 44% of Blacks and 16% of Whites. At APL 2 were 26% of Hispanics, 39% of Blacks and 34% of Whites. Only 18% of Hispanic adults were at the most advanced level, APL 3, and could be considered highly literate, compared to 17% of Blacks and 50% of Whites.

The English Language Proficiency Survey (ELPS) determined that while 13% of the population 20 years of age and older was illiterate, 48% of adults whose native language was other than English were illiterate. In total, the ELPS estimated that 17 to 21 million adults in the United States were illiterate. This study also determined that fully 22% of the illiterate adults in the United States were Hispanic, even though Hispanics totaled less than 6.4% of the adult U.S. population at that time. Thus between 3.7 and 4.6 million Hispanic adults were illiterate out of a total of about 9.6 million. This means that, according to the ELPS, between 39% and 49% of the adult Hispanic population was illiterate in 1982. Researchers analyzing ELPS data, however, feel that the figures used in the study were conservative and that the actual number of illiterate Hispanics was probably higher.

Rates of illiteracy are especially high for Hispanics because of the disproportionately high percentage of Hispanic youth leaving high school without a diploma. Hispanics leave school at earlier ages, completing fewer years of school, than other population groups. For example, 1987 data reveal that the median number of years of schooling completed by Hispanics 25 and over is 12.0, compared to 12.7 for non-Hispanics. The dropout rate for Hispanics is the highest for any major United States subpopulation; for Mexican Americans and Puerto Ricans it is estimated at 45-50%, and is over 70% in some large urban areas. Dropouts include both limited-English proficient and fluent-English speakers, and both groups often lack full English literacy.

The lack of full English proficiency among Hispanic and other language-minority group adults and out-of-school youth presents serious challenges to our nation. Illiteracy not only limits opportunities available for Hispanics to lead full, productive lives, but also places a serious strain on our economy. A well-educated and trained work force and literate citizenry are essential for American stability and international competitiveness in the 21st century.

Current public and private literacy efforts are inadequate to meet the need in the Hispanic and other communities. Thousands of Hispanic adults are placed on waiting lists for Adult Education and literacy classes yearly. Large urban centers such as Los Angeles, San Francisco and New York, as well as many rural areas, report a serious lack of resources for literacy programs. Los Angeles, for example, reports over 40,000 adults on waiting lists for adult education and English classes.

In addition, the demand for English literacy programs has increased greatly as a result of the Immigration Reform and Control Act of 1986. Individuals who wish to adjust their status from temporary resident to permanent resident under the new law must demonstrate an understanding of the English language and U.S. history and government or show enrollment in an approved course. Given the lack of programs that develop such skills, many Americans may be denied an opportunity to become legal residents as intended by Congress unless program capacity is expanded.

The English Literacy Grants Program in the Adult Education Act, as created by the Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988, is a promising -- though limited -- beginning to meeting the goal of achieving full literacy among Americans. This important program will provide grants for the operation of English literacy programs for adults and out-of-school youth with limited-English proficiency. An important aspect of this program is the reservation of funds for programs operated by community-based organizations, which are often the most effective in serving the populations most in need, such as individuals with limited-English proficiency.

The English Literacy Grants Programs is a modified version of the English Proficiency Act which was introduced by Rep. Matthew Martinez (D-CA) and Senator Jeff Bingaman (D-NM). This legislation enjoyed wide bipartisan support in both houses of Congress. The need for this program is demonstrated by the Congress' decision to include it in the omnibus education legislation recently signed into law by the President.

The National Council of La Raza strongly encourages this Committee to fully fund the English Literacy Grants Program at $26.3 million for Fiscal Year 1989. This program can make a significant contribution to improving the English literacy skills of thousands of Americans.

STATEMENT OF WILLIAM R. NESTER, PRESIDENT, KEARNEY STATE COLLEGE

My name is William R. Nester and I am President of Kearney State College, a four-year comprehensive institution located in central Nebraska.

There are 9,381 students (headcount) enrolled at Kearney State. Many of those students come to Kearney State from relatively isolated rural environments. Although students from 20 other states and more than 40 foreign nations attend Kearney State, more than 98 percent of the students are Nebraska residents.

Kearney State is committed to the open admissions policy of the State of Nebraska. This policy encourages individuals with disparate abilities and quality of preparation to enter the institution, as the State of Nebraska places relatively few requirements on the granting of high school diplomas. Thus, there are many students who begin their college careers with inadequate preparation and substantial learning deficiencies.

In addition, the level of funding for Kearney State is substantially lower than the funding for institutions of a comparable role and size. When the initial application for Title III funding was made for FY 1987, Kearney State ranked in the bottom one percent among public four-year institutions in educational and general expenditures per full-time equivalent student. The situation has not improved significantly in the two years since that application, although Kearney State is one of the few institutions in Nebraska which has continued to exhibit growth in student numbers.

The lack of adequate funding combined with significant growth at Kearney State has exacerbated the problem of outdated technologies for fiscal, administrative, academic, and planning functions. In addition, the significant number of students who are ill-prepared for college coursework places additional burdens on the faculty and staff resources at the institution. If those students are to grow and thrive in an academic environment, then obviously, greater resources must be utilized to assure a chance of academic success.

Title III administrators recognized these significant problems and awarded Kearney State grant money for a three-year period beginning in 1986. The first priority of the institution was to assist students in improving their writing, analytical and synthesis skills. Second, strengthening mathematical, analytical and reasoning skills was a priority. Finally, developing an effective transactional and management information system was of utmost importance from an institutional standpoint.

As we approach the third year of the three-year funding cycle, there is no doubt of the great benefit to Kearney State from the availability of this Title III grant. Our students are developing into better writers and more adept mathematicians. In addition, much of our obsolete computer equipment has been replaced with a system which combines transactional and management processing functions.

I obviously am concerned about the potential loss of that funding in the future. At the end of the current funding, Kearney State will have sufficient resources to integrate these new programs into our curriculum. However, there are other areas and programs which could be strengthened with Title III funding. One area of great importance to our institution is rural economic revitalization and development. Kearney State has taken the lead in Nebraska in offering programs which will enhance the rural economy, but we need money to get the program off the ground. Title III grants would be beneficial in that instance, and I am concerned that the money will not be available for that effort, an effort which will need the support of all entities of government.

I appreciate your time and concern relative to this issue. Thank you for allowing me the opportunity to address your committee.

STATEMENT OF RON DE LUGO, DELEGATE, VIRGIN ISLANDS

I come before this subcommittee to seek funding to continue two programs that are crucial to the U.S. Virgin Islands. First, General Education Assistance is vitally important for the territory to meet its goal of building, expanding and repairing many of its schools in the near future. Second, the Territorial Teacher Training Program is instrumental for the Virgin Islands and other insular areas to enable all their teachers to get their baccalaureate degrees or professional certificates.

I also have a statement from Virgin Islands Commissioner of Education, Dr. Linda Creque, who is submitting a detailed account of what these programs have accomplished in recent years and how the funds will be used in the future. Accordingly, I will just touch on several major points.

First, let me note that Congress has supported these programs each year, despite the Reagan Administration's efforts to eliminate or rescind the funding. I want to thank you, in particular, Mr. Chairman, for your deep commitment to improving the educational system in the Virgin Islands and other insular areas. You have been a great friend to the Virgin Islands' schools and, as a result of your efforts, many Virgin Islands students have been able to obtain a better education and prepare to build a better future for our islands.

Education remains one of the Virgin Islands Government's top priorities. The Department of Education's budget represents more than one-fourth of the Government's entire spending. Federal funds, including General Education Assistance, are used to supplement this substantial local commitment.

Nevertheless, 1987-88 has been a tough year for Virgin Islands schools. All three of our high schools have been closed at one time or other by students or teachers marching for better classroom conditions. I am submitting copies of stories from our local newspapers that describe these marches, and the efforts of our local administrators to resolve the problems. As you can see, a high school and elementary school were closed because of backed-up sewage. Another high school with the bare minimum of facilities is forced to use one building for its cafeteria, auditorium and gymnasium. They do their best and call it the "cafetorium." The only high school on the island of St. Croix is severely overcrowded as it serves over 2,500 students without basic music and laboratory facilities. The reports also outline electrical and structural problems in many of our schools. I believe these students were fully justified in their marches, which were well organized and peaceful. These students demanded the basic opportunity to get a good education and to prepare themselves for the adult world. No political pressures or budgetary politics should stand in their way.

The physical problems in our schools reflect the situation inherited by the new administration of Governor Alexander Farrelly and Education Commissioner Linda Creque, who took office just over a year ago. They have made a promising start. Governor Farrelly tackled the crisis head-on by declaring a state of emergency in education on February 5, 1988. The Farrelly Administration, along with the 17th Legislature, budgeted an extra $1.3 million for immediate school repairs.

In light of these severe problems, and the genuine efforts of the Virgin Islands Government to correct the problems, the President's budget message in regard to General Education is incomprehensible. While the President has never sought funds for this program, this year he argued that the funds are not needed because of the substantial school construction in recent years. But, in fact, Virgin Islands schools remain overcrowded and plagued by the unusual construction, erosion and flooding conditions that prevail in the islands. St. Croix, which has a larger population than St. Thomas, still has only one high school, compared to two for St. Thomas. A second high school for St. Croix, at a cost of $12 million, is imperative. The need for General Education Assistance remains great.

Virgin Islands schools continue to serve students from throughout the Caribbean, whose parents have been attracted by the economic opportunities available under the United States flag. Most of these people are relatives of West Indians who have become naturalized citizens and whose family members now join them in the Virgin Islands. In addition, other West Indians who qualify under the quota system to emigrate to the United States actually choose to come to the Virgin Islands. Our islands' educational system was severely strained when the Federal Court ruled that the children of non-citizens should be able to attend public schools (Hosier v. Evans). Since then, we have built 13 schools and educated more than 30,000 of these students in our educational system. But we still have three times as many non-citizen children, on a percentage basis, than the states with a large non-citizen population. Non-citizen children make up 9.9 percent of our student population, according to recent count, compared to 3.2 percent in California and 3.5 percent in Texas.

Accordingly, Mr. Chairman, I am asking this subcommittee to approve the appropriation of $5 million for General Education Assistance, the full amount authorized in H.R. 5, which was just approved by both houses of Congress last month. Congress has appropriated this full amount for the last two years, and now the Virgin Islands needs ongoing support to continue the improvements it has been making.

The Territorial Teacher Training Program is another solid Federal program that has had a marked effect on the schools in the Virgin Islands and other insular areas. This program, authorized at $2 million for all the insular areas, has enabled the Virgin Islands to train many of its long-term teachers or para-professionals and bring them up to accepted professional standards.

These are the natives and the people who have made a commitment to the Virgin Islands, the people who will remain in the islands long after they get their training. As such, the Teacher Training Program helps reduce our reliance on teachers from the mainland, many of whom are not prepared to deal with the cultural differences in our islands and among our students. Reliance on such teachers have produced severe problems in the past.

Last year I reported that 77 Virgin Islands teachers had completed their training through this program. Now, as a result of the actions of this subcommittee, I can report that another 285 teachers took classes last year, with 12 earning baccalaureate degrees and 22 earning professional certificates.

But the problem is far from solved. I am informed that 210 of the 1,658 public school teachers in the Virgin Islands last year were not degreed, and another 110 had their degrees but did not meet minimum certification requirements. The Department of Education and University of the Virgin Islands have a cooperative agreement to train these individuals. The Teacher Training Program is well established and will be at full enrollment for the forseeable future.

In his budget message, President Reagan also recognized the value of this program. I urge you to approve the full $2 million for all the insular areas, as was authorized in H.R. 5.

Mr. Chairman, these programs have proven themselves over the years. Thanks to Congress' initiative, these programs have produced positive results. I urge this subcommittee to keep its commitment to these important programs in the U.S. territories throughout the appropriations process. I realize we are contending with a federal deficit, but it would be shortsighted and counter-productive to abandond solid educational programs for the sake of slight savings.

I would be happy to answer any questions the Members of this Subcommittee may have regarding these two programs, and thank you for your consideration.

STATEMENT OF JOHN PAUL HAMMERSCHMIDT

MR. CHAIRMAN, MEMBERS OF THE SUBCOMMITTEE, I AM HERE TODAY TO REQUEST THAT YOU PROVIDE FULL FUNDING, $10 MILLION IN FY 89, FOR THE OUTREACH PROVISION IN THE 1987 OLDER AMERICANS ACT AMENDMENTS. THIS PROVISION, WHICH I AUTHORED, WILL UTILIZE STATE AND AREA AGENCIES ON AGING TO LOCATE LOW-INCOME OLDER PERSONS WHO ARE ELIGIBLE FOR, BUT NOT RECEIVING, SUPPLEMENTAL SECURITY INCOME (SSI), MEDICAID, AND FOOD STAMPS, AND ASSIST THEM IN OBTAINING THESE ESSENTIAL BENEFITS.

THESE PROGRAMS--SSI, FOOD STAMPS, AND MEDICAID--HAVE THE CAPACITY TO ELIMINATE MANY OF THE HARDSHIPS OF EXTREME POVERTY IN THE NATION. HOWEVER, A RECENT STUDY SPONSORED BY THE COMMONWEALTH FUND HAS REVEALED THAT ONLY HALF OF THE ELIGIBLE ELDERLY PARTICIPATE IN SSI. IN ADDITION, IT HAS BEEN FOUND THAT ONLY ONE-THIRD OF THE NON-INSTITUTIONALIZED LOW-INCOME ELDERLY PARTICIPATE IN THE MEDICAID PROGRAM, AND ONLY FIFTY PERCENT OF THE LOW-INCOME ELDERLY ARE ENROLLED IN THE FOOD STAMP PROGRAM. THE DATA MAKE IT CLEAR THAT THESE PROGRAMS ARE FALLING FAR SHORT OF ACHIEVING THEIR POTENTIAL.

THE COMMONWEALTH FUND STUDY ALSO REVEALED THAT MANY OF THOSE OLDER PERSONS WHO WERE ELIGIBLE FOR BENEFITS HAD NO KNOWLEDGE ABOUT THE PROGRAMS OR WERE UNDER THE MISTAKEN IMPRESSION THAT THEY WOULD NOT QUALIFY. IT HAS BEEN ESTIMATED THAT THERE MAY BE TWO MILLION OLDER PERSONS WHO ARE ELIGIBLE FOR BENEFITS AND NOT RECEIVING THEM. MANY OF THESE PEOPLE ARE LIVING ON LESS THAN $85.00 A WEEK.

SINCE 1959 THE POVERTY RATE FOR THE ELDERLY HAS DECREASED SIGNIFICANTLY. THERE ARE HOWEVER, STUBBORN POCKETS OF POVERTY AMONG THE ELDERLY. POVERTY IS GENERALLY HIGHER AMONG OLDER WOMEN, MINORITIES, IN RURAL COMMUNITIES, AND FOR THOSE OVER AGE 85. NOT SINCE 1974 HAS OUR NATION UNDERTAKEN ANY SIGNIFICANT OUTREACH PROGRAM FOR THE ELDERLY. IT IS TIME FOR US TO FIND THIS UNDERCLASS OF OLDER PERSONS AND PROVIDE THEM WITH THE OPPORTUNITY TO RECEIVE THE BENEFITS TO WHICH THEY ARE ELIGIBLE.

I DON'T BELIEVE THAT ANYONE CAN CLAIM THAT THESE BENEFITS ARE TOO GENEROUS; IN A TYPICAL SITUATION AN OLDER INDIVIDUAL RECEIVING SOCIAL SECURITY, SSI AND FOOD STAMPS WOULD ONLY BE AT 84 PERCENT OF POVERTY. A MARRIED COUPLE IN COMPARABLE CIRCUMSTANCES WOULD BE AT 99 PERCENT OF THE POVERTY LINE.

THE OUTREACH PROVISION IS ONLY AUTHORIZED FOR TWO YEARS. THEREFORE IT IS IMPORTANT THAT FULL FUNDING BE PROVIDED. CONGRESS CANNOT REMAIN COMPLACENT BECAUSE WE HAVE AMELIORATIVE LEGISLATION ON THE BOOKS. TWO MILLION OLD PEOPLE LIVING FAR BELOW THE POVERTY LINE COMPEL ADDITIONAL ACTION. I URGE YOU TO APPROPRIATE $10 MILLION IN FY 89 AND FY 90.

THIS PROVISION HAS THE SUPPORT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS, THE NATIONAL COUNCIL OF SENIOR CITIZENS, THE NATIONAL CAUCUS AND CENTER ON THE BLACK AGED, THE NATIONAL SENIOR CITIZENS LAW CENTER, THE NATIONAL ASSOCIATION OF STATE UNITS ON AGING AND THE NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING.

STATEMENT OF THE HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

I appreciate the opportunity to appear before you today and present testimony in regard to our request for continued support for the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC). For the record, my name is Stephen Barrett, and I am the new Director of the Helen Keller National Center, having assumed that office on April 27, 1987.

My purpose today is to provide you with brief background information on the history and goals of HKNC, recent accomplishments, our goals for the coming year, and fiscal implications. I wish to address very specific service priorities in terms of their benefit to persons who are deaf-blind, their implementation, and why we feel they will have an important impact on services on a national basis.

The Helen Keller National Center is funded exclusively by Congress. For federal FY '89 the Reagan Administration has proposed level funding for HKNC in the amount of $4.8 million. There is no inflationary increase proposed, which concerns us very much. We are asking Congress to provide funding at the level of $5.3 million level, not only for our concerns over modest inflation, but so that we may expand services in several key areas which are described herein.

AUTHORIZATION AND PURPOSE

The Center is authorized under Title IX of the Rehabilitation Act Amendments of 1986 and operates under the general supervision of Rehabilitation Services Administration, OSERS, U.S. Department of Education.

The purpose of the Helen Keller National Center is to provide a national program of rehabilitation services to America's estimated 40,000 persons with deaf-blindness. We accomplish this in many ways. During the twelve month period ending June 30, 1987 the Center served over 1400 persons at its rehabilitation center based at its headquarters on Long Island, New York and throughout the nation.

When Congress established the Center in 1969, the following objectives were mandated:

1. To provide a program of multidisciplinary evaluation to those deaf-blind persons for whom rehabilitation seems feasible to determine their rehabilitation needs, interests, and potential.

2. To provide individualized rehabilitation training, based

on the findings of the evaluation, to achieve, as required in each case, (a) meaningful contact with the environment and effective means of communication, (b) constructive participation in the home and community, (c) initial or enhanced employability, and (d) any other development important to the optimum rehabilitation of the deaf-blind individual.

3. To provide training for new and prospective specialists in services to deaf-blind persons.

4. To provide community education designed to sensitize both the lay and professional communities to the special needs and normal aspirations of deaf-blind persons and to develop in the community an acceptance of and confidence in persons who are deaf-blind.

5. To identify and locate youths and adults who are deaf-blind in order to develop a national register of these individuals which will provide information as to the composition and distribution of the deaf-blind population that will be helpful in the planning of services appropriate to the needs and interests of this population.

6. To encourage the initiation of and to cooperate in medical research into the causes of deaf-blindness and methods of reducing or eliminating these causes.

7. To conduct research into the implications of deaf-blindness for the personal adjustment, education, and rehabilitation of the deaf-blind individual.

8. To innovate and/or improve approaches and techniques of rehabilitation that will best contribute to the promotion of the personal adjustment, education, rehabilitation and social and economic effectiveness of the deaf-blind individual.

9. To conduct studies, including follow-up studies of clients, to evaluate the effectiveness and appropriateness of services offered by HKNC.

10. To design and/or improve sensory aids that will reduce the handicapping effects of deaf-blindness.

11. To encourage and assist public and private agencies to develop services for deaf-blind persons in their local communities.

DIRECT SERVICE TO DEAF-BLIND PERSONS

All persons accepted at HKNC for evaluation and training have both deafness and blindness and many have additional disabilities as well.

The rehabilitation training program at headquarters provides a comprehensive program of personal adjustment evaluation, training, vocational preparation, job placement and follow-up. Areas of personal adjustment training include communication skills, orientation and mobility, daily living skills, home management, audiology, speech therapy, vocational adjustment, work experience, social services, counseling, and others. Clients are referred to the Center by state rehabilitation agencies across the nation.

The Center provides a continuum of vocational services as a part of its overall rehabilitation program. These include vocational assessment, work adjustment, and our Community Work Experience Program, based upon a Supported Employment model, which offers the opportunity for employment training on real jobs in the community. Job placement in the clients' own state and local community is an additional part of the emphasis placed upon follow-up services by HKNC.

A very important goal of the rehabilitation program is to offer clients meaningful experience which will enhance their ability to live as independently as possible in their own community. Much of the training program takes place in the nearby community, giving clients experiences they will need and use once they complete our training program and return to their home community.

Training for independent living includes shopping trips, using the local bank and post office, dining out in local restaurants and fast food establishments, visits to local stores, and contact with all the local community has to offer.

The best overall evaluation of the relevance and appropriateness of rehabilitation training offered by the Center is what happens to and for the clients once they return home. Planning for transition back to the home community is a cooperative effort involving staff at headquarters, field staff of the Center, and local staff and resources of the State Vocational Rehabilitation agency. HKNC provides assistance in job placement and establishing the best possible community living arrangement for the individual.

HKNC does not have a case closure system - its follow-up services continue indefinitely in order to assure the individual continues to receive whatever support services they require at any time in their life.

FIELD SERVICES IN THE LOCAL COMMUNITY

The Center operates an extensive system of Field Services aimed at providing services to deaf-blind people in their local communities. The Center has ten regional offices staffed by one or more professionals whose goal is to provide training and technical assistance to local service providers. They identify the deaf-blind population, assess the needs of its individual members, and develop and implement a plan of service based upon needs of the individual.

The Center's Regional Representatives provide valuable assistance in developing employment training opportunities, assistance with job placement, family counseling, and referral.

HKNC has also provided over 1.6 million dollars of direct support for development of a national network of Affiliated agencies. This seed money has allowed some thirty state and private agencies to establish local service projects. Seed money has been used to cover the salary, fringe, training, travel and other direct costs associated with development of specialized services for deaf-blind people within these agencies.

RESEARCH

At present there are a number of research projects being conducted at or by HKNC, including those initiated by HKNC and those in which we formally cooperate with universities or other organizations.

Current projects include testing of a braille computer interface terminal and a braille television captioning project in conjunction with Science Applications International- a Maryland research and engineering corporation. These projects are funded by the National Institute on Disability and Rehabilitation Research.

We are also conducting studies on the effects of the rubella virus in adulthood and community-based service needs of elderly persons with deaf-blindness. We currently have other research projects with Mississippi State University and the University of California at San Francisco on various aspects of services to deaf-blind persons.

COMMUNITY EDUCATION

The purpose of our Community Education department, under the leadership of Dr. Robert Smithdas who is himself deaf-blind, is to educate the lay and professional public as to the needs of deaf-blind persons, their capabilities, and their employability.

OUR PRESENT CONCERNS WITH FUNDING

If funding is approved in the amount of $5.3 million it will allow us to accomplish the following goals:

1. Expand our current employment training programs. At present we are limited in the number of employment sites we can establish only by the fact that we have staff limitations. The model of Community Work Experience we utilize, based upon Supported Employment theory, has already been proven effective. We are requesting funds to add two Employment Training Specialist positions who will work directly with our clients on the job site. This will allow us to double the number of job training sites in the community and the number of persons served.

2. Increase the number of staff in our regional offices. With funding provided this year we have begun a process of adding a second person to each regional office based upon recommendations from Rehabilitation Services Administration, the governmental office under whose supervision we operate. Two new staff have been added, one each to our Atlanta and Seattle offices, and we are recruiting for a third position which will serve elderly persons with deaf-blindness.

These positions are vital to the provision of local services to deaf-blind persons and for support to local and state agencies attempting to develop and/or expand current services. Some of our ten regions are quite large and it is very difficult to provide the quality and quantity of services needed with only one staff person per region.

If funding is approved, we would add three new positions to our regional offices in order to gradually increase the number of staff in these positions. The result will undoubtedly be a measurable increase in the numbers of persons served in their local community.

3. Comply with the anticipated salary and fringe increases expected with settlement of a new union agreement. Our current

union agreement is up for negotiation next spring. We anticipate the settlement will call for at least a 4-5% increase in salary, which also increases our cost of fringe benefits. Without funding to help cover these increases and the normal inflationary increases expected from year to year in any organization, our only alternative would be to eliminate vital staff positions.

4. Necessary Plant Improvements. Our current facilities, though modern and well maintained, could benefit from modern technology to effect energy cost savings. Our furnishings in many parts of the three buildings on campus are the original ones installed in 1976. We have begun a plan of action to gradually replace worn equipment and furniture. Our residence building, which provides room and board for a maximum of 52 clients, is badly in need of new furnishings.

We have a general concern that the Administration's request for level funding for HKNC in FY '89 will not allow us to deal effectively with even modest increases in operating costs. Expenses for utilities, food, transportation, medical services, and others will undoubtedly increase.

REQUEST FOR INCREASED APPROPRIATION

HKNC respectively requests an appropriation for FY '89 of $5.3 million, as opposed to the Reagan Administration's request for level funding of $4.8 million. A breakdown of this increase is based upon the following goals:

1. Expand Employment Training Services- Two positions, salary and fringe- $54,000.

2. Expand Services to Local Communities- three new positions in regional offices- salary, fringe and related costs- $138,000.

3. Impact of New Union Agreement- $198,000.

4. Plant Improvements- $110,000.

CONCLUSION

Individuals with deaf-blindness are perhaps the most severely handicapped population known to man. The Helen Keller National Center for Deaf-blind Youths and Adults provides the highest quality services possible in a program which is internationally recognized as a leader in the field of Vocational Rehabilitation.

On a national basis we are proving everyday that people who are deaf-blind can lead meaningful lives living and working alongside their fellow members of the community. The financial costs of rehabilitation can be measured and the return on every dollar spent has been proven to be a remarkable investment repaid many times over as tax consumers become taxpayers.

Each year brings new ideas, service strategies, and increased opportunities for persons who are deaf-blind. There has been considerable growth at Helen Keller National Center in terms of both the quantity and quality of services provided. We need your continued support to help people who are deaf-blind attain the same quality of life we desire for ourselves.

STATEMENT OF THE AMERICAN ASSOCIATION OF SCHOOL ADMINISTRATORS

Mr. Chairman, while this is another difficult budget year, the Congress has recognized education as a major national priority in the House and Senate budget resolutions. And we believe there is ample room within those resolutions and within the November 1987 Executive/Legislative Economic Summit agreement for the increases we are recommending.

Before we list our priorities we would like to emphasize a fact that you already know: this nation will not be able to make economic progress unless we address the needs of the growing numbers of disadvantaged young people entering our schools. Last year the business-oriented Committee for Economic Development in its report, Children In Need, stated:

> "For generations, the American Dream has been to live in freedom and to have the opportunity to pursue a satisfying life, reap the benefits of economic prosperity, and partake of the privileges and responsibilities of citizenship in the world's foremost democracy. But as we stand on the threshold of the twenty-first century, that dream is in jeopardy. This nation cannot continue to compete and prosper in the global arena when more than one-fifth of our children live in poverty and a third grow up in ignorance."

And the Carnegie Foundation in its report, An Imperiled Generation--Saving Urban Schools, released just last month, said, "...change will come only when the nation wills it. The greater the delay, the greater the cost."

The Committee for Economic Development recommended full funding of Chapter 1 and Head Start so that all eligible children may be served. While we realize that budget constraints will not permit an immediate move to full funding, we would urge you, Mr. Chairman, to adhere to the recommendations of H.R. 5, the Hawkins-Stafford Elementary and Secondary School Improvement Amendments of 1988, which won final approval in the House on April 19 in a 397-1 vote and in the Senate on April 20 in a unanimous vote. The Declaration of Policy and Statement of Purpose in H.R. 5 proclaims:

> "The Congress declares it to be the policy of the United States to expand the program authorized by this chapter over the next 5 years by increasing funding for this chapter by at least $500 million over baseline each fiscal year and thereby increasing the percentage of eligible children served in each fiscal year with the intent of serving all eligible children by fiscal year 1993."

Therefore, we would respectfully ask that your committee adhere to the Hawkins-Stafford Amendments and appropriate to Chapter 1 Compensatory Education for Disadvantaged Children $500 million beyond what is necessary to cover the cost of inflation. We understand that most of that increase will be dedicated to support the new Grants for Local Educational Agencies in Counties with Especially High Concentrations of Children from Low-Income Families. We fully support that provision of H.R. 5 as well, since it will help direct much of the new resources made available by your committee to those areas of the country and those children most in need of compensatory education assistance.

Also contained within H.R. 5, which is the most comprehensive, far-reaching education legislation enacted by Congress in more than a decade, are a number of worthy new or expanded programs, for which we would urge your committee to provide new funds. Foremost among these programs are:

•**Secondary School Programs for Basic Skills Improvement and Dropout Prevention and Reentry**, which will help local educators expand Chapter 1-type services beyond the elementary grades and initiate new programs aimed at preventing students from dropping out of high school, where we are losing so many of our young people today.

•**Magnet Schools Assistance**, which is a true linchpin in many school desegregation plans through its promotion of excellence in education for all children.

•**Even Start**, a new program that establishes a critical link between educationally disadvantaged young people and illiterate parents, so that they may learn together the key elements necessary to help them both escape the vicious cycle of poverty.

We would also ask that your committee continue its strong support for Impact Aid, the Chapter 2 block grant, Drug Free Schools Act and Vocational Education.

Next, Mr. Chairman, we would like to focus our attention on the need for additional assistance to education for handicapped children.

Under Public Law 99-457, enacted in 1986, local schools will be required in the 1990-91 school year to provide preschool services to handicapped children. As an incentive to achieve earlier, voluntary compliance with this new law; Congress assured those districts, which opted to begin compliance before the mandate took effect, that they would be provided $3,800 per pupil (one-half of the start-up cost) for each new preschool child they began to serve in 1987, 1988 and 1989.

Because Department of Education estimates, as well as estimates of professionals in this field, failed to account for demographic shifts (brought on by family moves in a changing economy) involving some 10,000 children; and because we all underestimated a small but significant growth in the numbers of children who need these services; the **Preschool Incentive Grants** program under the State Assistance category in the Education for the Handicapped program requires $171.2 million in new funds in Fiscal Year 1989. That increase would bring the total for the Preschool Incentive Grants program to $372.2 million in Fiscal Year 1989. Up until this point your committee, Mr. Chairman, has been acting under the sound advice of the authorizing committee, which depended on education community estimates in establishing a funding recommendation for Preschool Incentive Grants. No one foresaw the population shifts and growth among preschool handicapped children that began to appear at local schools this year, and we would be grateful for your help in remedying this problem.

Meanwhile, for the regular State Grant Program which helps serve school-aged children under the Education for the Handicapped Act, we respectfully seek $130 million in new funds, an increase of nine percent over Fiscal Year 1988. If we ever hope to achieve a federal funds figure even close to the 40 percent of average local per pupil costs for assuming this important mandate, the State Grant Program must continue to grow at a rate that exceeds inflation. The modest increase we are suggesting will provide for some reduction in the burden on local schools, but will not lift the federal share much above the 10 percent level we have achieved in the past few years under your leadership, Mr. Chairman.

Finally, we would ask that you continue to look favorably on a few small, but nontheless signficant programs that you and the committee have supported over the years and that are bringing professional revitalization to educators across the nation. They are:

***The Leadership in Educational Administration Development (LEAD) Program**, which helps improve the management and leadership skills of practicing school administrators.

***The Professional Development Resource Centers**, which help stimulate professional growth among our corps of existing teachers.

***The Paul Douglas Teacher Scholarships** (formerly Congressional Teacher Scholarships), which provide college student aid assistance to talented high school students who intend to pursue teaching careers.

Mr. Chairman and members of the subcommittee, we at AASA believe the budget resolution contains sufficient authority to allow you to seriously consider our recommendations. We thank you for your past commitment to education and the nation's children. We thank you for your votes last month for an excellent education reauthorization bill, H.R. 5. And we urge you to follow through on its promise to America's young people by committing funds to its programs, so that through your Fiscal Year 1989 appropriations bill, education will remain at the top of our list of vital national investments.

STATEMENT OF THE ALAN GUTTMACHER INSTITUTE

The Alan Guttmacher Institute (AGI) is an independent, nonprofit corporation for research, policy analysis and public education in matters related to reproductive health and population. We appreciate the opportunity to submit a statement on a matter that we believe deserves your concerted attention, because it is of importance to men and women of childbearing age throughout the country: contraceptive availability.

Increasing the availability and effective use of contraceptives by American couples could -- and should -- be linchpins in our attempts to confront and arrest two haunting social problems: unacceptably high rates of infant mortality in the United States and high rates of recourse to abortion in the United States. While these two issues are not often spoken of in the same breath, because their politics are perceived to be quite different, they are, in fact, closely related in that both problems could be alleviated in large measure by helping American couples to avoid unintended and mistimed pregnancies.

In 1980, the U.S. Surgeon General set a national goal of reducing infant mortality rates among minorities and low-income women by almost half by the end of this decade. However, in a "Midcourse Review," released only a few months ago, Dr. Koop concluded that the nation will not meet its goal by 1990 - possibly not even until the end of this century. Low birthweight is the major factor associated with the death of infants in the first four weeks of life. As a society, one thing we clearly must do to address this problem is to provide access to high quality prenatal care for all expectant mothers in our country -- and your personal efforts in that regard are to be highly commended. At the same time, we must note that, according to a major report by the National Academy of Sciences' Institute of Medicine (IOM), the first step in reducing both low birthweight and the resulting high infant mortality rates is the prevention of unintended births to "high risk" women. These women include teenagers, women who have only short intervals between pregnancy, women of low socioeconomic status, women with lower levels of education, and those who are unmarried. Among the IOM's specific recommendations was increased access to family planning services, with special emphasis on reaching low-income women and unmarried teenagers under 18. The importance of the federal Title X family planning program in accomplishing this objective was specifically emphasized.

At the same time, reducing rates of unintended pregnancy clearly will also help to reduce recourse to abortion in the United States. This holds true both for teenagers and for adult women. Teen pregnancy was the focus of another recent National Academy of Sciences' report, one released last December by its National Research Council. This report made special note of the fact that the painful controversy surrounding abortion has only exacerbated our society's difficulties in addressing the national problems of adolescent childbearing and parenting. Yet, ironically, reducing unintended pregnancies would offset the necessity for many abortions now sought by adolescents in the first place. While recognizing that "there are no easy answers or quick fixes," the NAS report concluded that adolescent pregnancy prevention should be our nation's top priority in this area and that the availability of contraception is the surest strategy -- the most effective intervention we have -- for implementing this goal.

It seems clear that better contraceptive use should be able to make major inroads towards ameliorating both the very serious societal problem of infant mortality and the equally serious -- and politically explosive issue of unintended pregnancies and abortion. However, no such strides can be made unless contraceptives are both available and effectively used. It has been well established that contraceptive prevalence and consistent use are higher where there is a greater selection of contraceptive methods. Yet, for a plethora of reasons, the shocking fact is that U.S. women and men are in the unique if unenviable position of losing contraceptive options at the same time that new methods are being regularly introduced around the world. Studies performed by the Alan Guttmacher Institute have revealed a range of obstacles currently facing contraceptive research, development and marketing in this country. Please find attached an article summarizing and updating the results of those studies. These obstacles may be daunting, but hopefully they are not insurmountable. Prominent among them are insufficient and unstable funding, which has declined worldwide by about 25 percent in real dollars since the mid-1970s; the high cost of liability insurance for contraceptive products, which together with the virtual impossibility of obtaining insurance for clinical tests on humans, is leading to a near-paralysis of research into new methods; and the complex premarketing requirements and regulatory procedures of the FDA which delay approval of many methods for use in the United States. Not surprisingly, only one private U.S. pharmaceutical company remains in the business of conducting contraceptive research and development directed towards the U.S. market.

While no single entity, including the U.S. government, can solve this problem in its entirety, the problem will only grow worse if not addressed. The key is to increase both the amount and the stability of government funding for research leading to contraceptive development, thereby opening the door for new methods that will be safer, more effective and more accessible to the individuals who need them most. At the same time, continued government efforts to evaluate the safety and efficacy of methods now in use also are critical. Such government research can be critically important in debunking myths surrounding certain methods -- particularly the birth control pill -- that still are pervasive in our society. Accurately altering people's erroneous perceptions of the health risks and benefits of certain contraceptives can lead to better use by allowing Americans to take full advantage of the few options still available to them.

Recognizing the need to accelerate the development of new contraceptive methods, and to ensure the continued safety and efficacy of existing ones, the

National Institute of Child Health and Human Development (NICHD) designed a Contraceptive Development Initiative some two years ago. While the initiative has produced some progress in a few areas, it is clear that it has not been able to meet its full potential due to lack of adequate funds. Accordingly, we commend to the committee's consideration an additional $10 million in FY 1988 funding for NICHD, directed specifically toward this initiative. There can be little doubt of such an initiative's cost-effectiveness in both human and economic terms over the long run.

STATEMENT OF THE AMERICAN FEDERATION OF TEACHERS

On behalf of the American Federation of Teachers I would like to express our gratitude for your continuing leadership in the struggle to provide essential resources for the nation's schools, higher education institutions, and the students they serve. Your actions have demonstrated an appreciation of the important national concerns which must be addressed through increased financial support for education. In each year since the present Administration assumed office, Congressional appropriations for education have been substantially above the President's budget request.

The President's budget requests for education have been erratic, both in amounts and justifications. Repeatedly the Administration has reversed its course - in the level of funding and in the selection of programs proposed for expansion or elimination. This year, an election year, the President asked Congress for an overall increase in education funding. Although we welcome this change of heart, the President's budget for education is still inadequate.

For F.Y. 1989 the President requested what would be a 4.2 percent increase over F.Y. 1988, an increase roughly equivalent to inflation. Ironically, the total amount is 50 percent more than he requested for F.Y. 1988. Although it includes increases for some education programs, the Administration would eliminate a number of other, essential programs and freeze the funding levels of the remainder. The President's request would cannibalize important, lesser-known programs in order to find the dollars to increase other programs.

Fortunately Congress and its leaders have recognized education as a necessary and fundamental investment in the nation's future. This was evident in numerous hearings conducted during this Congress on the importance of educational investment in reestablishing American economic competitiveness. It was also evident in the response by Majority Leader Robert Byrd and Speaker Jim Wright to the President's State of the Union Address. It was most recently evident in the passage of H.R. 5, which contains a number of new educational initiatives that will help produce a more productive and competitive work force.

The American Federation of Teachers urges the Subcommittee to continue recognizing investment in education as a national priority as it performs its responsibility in drafting an appropriations bill. First, AFT recommends the Subcommittee adopt an inflation adjustment for all education programs. This is necessary to maintain the current level of services and to provide a strong base for additional services. In addition to the adjustment for inflation, AFT recommends investment in the new initiatives encompassed by H.R. 5. Confronted as the nation is by an increase in poverty, yet a growing shortage of skilled workers, we must improve the ladder of educational opportunity for disadvantaged youth, recapture school dropouts, and reinforce programs for students with special needs. In the future the United States cannot afford the inefficiency of poorly educated and unemployable young people.

Reauthorized within H.R. 5, Chapter One contains several new provisions that will clearly enhance the effectiveness of this already outstandingly successful program. Concentration Grants, authorized to receive the first 400 million dollars above the current appropriations for Basic Grants, will help schools that have the highest population densities of disadvantaged students. Clearly such schools face greater pedagogical challenges and require greater resources to deal with these challenges.

Even Start, authorized at 35 million dollars, will extend Chapter One services to young children, one to seven years old, and to their parents. We know that providing services to children at an early age is more educationally effective and cost efficient. We also know that simultaneously providing assistance to parents, so they can better encourage and help their small children, greatly improves the results. Similarly, the Basic Skills Improvement Program, authorized at 200 million dollars, will provide additional help for disadvantaged students at the secondary school level. Such help is often necessary to maintain and improve upon the gains made under Chapter One at earlier grades. Dropout Prevention, authorized at 50 million dollars, will fund demonstration projects on methods of preventing students from dropping out of school, or of recapturing those who have already left.

The Magnet Schools Program, with its authorization increased by 90 million dollars, provides grants to schools that specialize in academic areas such as music, math and science, or foreign language. These schools are designed to attract students from diverse backgrounds as part of desegregation plans. However, they quite obviously increase the pool of disadvantaged students who receive strong academic training.

In addition to the new initiatives contained in H.R. 5, the American Federation of Teachers recommends additional funding for Education of the Handicapped. In spite of a federal commitment to provide up to 40 percent of the national average per pupil cost, to defray the excess cost of educating handicapped children, the federal contribution now stands at less than ten percent. This low figure is compounded by an underestimation of the number of children who must receive preschool services. Approximately 200 million dollars above an inflation adjustment for handicapped education will be required to fully fund the Preschool Incentive Grant Program.

At the higher education level, Pell Grants have put the opportunity to achieve a college degree within the reach of many disadvantaged students. As stated in the President's budget, an appropriation of 750 million over F.Y. 1988 would provide a maximum individual grant of $2,300 dollars. A significant investment is needed in this program, to help disadvantaged students meet rising costs of higher education and to reduce their dependence upon loans. As the first G.I. Bill demonstrated many years ago, this type of investment will surely pay for itself many times over.

Given the critical problems facing schools, and given the movement for educational reform throughout the United States, research and data collection have taken on even greater importance. It is particularly appropriate for the Federal Government to fund such activities. The AFT strongly supports the Administration's request for 81 million dollars for F.Y. 1989 funding of the Office of Educational Research and Improvement. Representing an increase of 13.5 million dollars, most of the new funds would be used to expand and upgrade statistical data collection efforts such as the National Assessment of Educational Progress, and for projects to collect data on school dropouts, school staffing, and related concerns. This information is vitally important to the success of the reform movement.

Three programs worthy of special note are the Christa McAuliffe Fellowships, the Paul Douglas Scholarships, and Leadership in Educational Administration Development. These programs offer respectively, sabbatical fellowships for teachers who have demonstrated unusual merit, scholarships for academically proficient high school students who wish to become teachers, and in-service training for school administrators to improve their administrative skills. Each plays an important role in improving the quality of school staff and should be fully funded.

Finally, the American Federation of Teachers would like to call your attention to the Special Assistance for the Virgin Islands, authorized in H.R. 5 for 5 million dollars. This authorization recognizes the special responsibility for education in the Virgin Islands and should be funded accordingly.

Mr. Chairman and Members of the Subcommittee, the American Federation of Teachers again thanks you for your continuing support of education. AFT looks forward to continuing its work with you to improve and strengthen educational opportunity for all Americans.

STATEMENT OF DR. W. MICHAEL EASTON, PRESIDENT, WESTERN MONTANA COLLEGE

In the spring of 1985, students, staff, faculty and administrators of Western Montana College came together to establish the long range objectives required to address deficiencies, improve quality, and enhance opportunity for future development toward self-sufficiency. Those objectives became the framework for our Title III Strengthening Institutions Program Grant.

At the mid-point of this five-year development program, the College can look with pride to the accomplishments to date. We have initiated programs for enhancing opportunities for success for academically underprepared students; improving career decisions for students from isolated rural communities; improving preparation of future teachers for Montana's rural schools; and establishing new degree programs that address the employment and training needs of southwestern Montana. Progress toward accomplishing these objectives has been a source of pride and encouragement to the College and the citizens of Montana during a time of economic difficulty and diminishing state resources.

We are at a critical juncture in this developmental program. Program additions and enhancements have been planned, implemented on a trial basis, and evaluated. The full implementation of these changes is beginning and, if enabled to continue, will result in improved academic quality, institutional management, and fiscal stability. The purpose of the Strengthening Institutions Program will have been met and Western Montana College will continue its contribution to the higher education resources of the nation.

Appropriations for Fiscal Year 1989 will not adequately fund currently approved Title IIIA four-year institutions. The resulting forty percent reduction in our fourth year award will not only curtail further program development, but also threaten the continuation of programs being implemented. On behalf of Western Montana College, I request the Committee to adequately fund Title III to enable continuing four-year institutions to complete their previously approved programs.

STATEMENT OF THE CLOSE UP FOUNDATION

Mr. Chairman and distinguished Subcommittee members, my name is Steve Janger. As President of the Close Up Foundation, it is an honor to appear before you today to respectfully request continued funding of the Allen J. Ellender Fellowship Program for Fiscal Year 1989. As you know, Close Up is a nonprofit, nonpartisan organization which conducts the largest government studies program in the country. Since 1973, it has been our distinct privilege to administer the Ellender Fellowships.

I have appeared before this Subcommittee numerous times and, each year, I have restated our ongoing commitment to motivate secondary school students to become active participants in our democratic system of government. I have tried to describe our efforts to reach out to the disadvantaged and to new and neglected constituencies, and have outlined initiatives undertaken to respond to areas of unmet needs.

BACKGROUND ON THE ELLENDER FELLOWSHIP PROGRAM

Throughout the years, I have reported proudly on the expansion of the student and teacher program to all 50 states, the District of Columbia, the Commonwealth of Puerto Rico, and the United States territories. With ever growing enthusiasm, I have presented information about the launching of our Citizen Bee competition, the widespread use of our publications, and the broad growth of our community-based government studies activities. I have been delighted to present statements regarding our use of telecommunications technology, an important dimension to our programs which has extended learning outreach throughout the country. I have always been pleased to emphasize that the federal seed monies are used as a catalyst to create civic learning opportunities for thousands of students and teachers across the country.

Looking back, it seems that each year I have made the statement that our work is more challenging and exciting than ever before. This year, however, there is a renewed and intensified spirit among Close Up staff. It is gratifying to see the general public's growing recognition of the need to make civic literacy a priority. Our spirits are buoyed by what we believe is the beginning of an important nationwide consensus to change the current condition of civic education. At the same time we, at Close Up, have been overwhelmed by the favorable comments of educators across the country about our wide range of civic education programs. A Social Studies Curriculum Coordinator from North Carolina wrote:

> The participation of our schools in the program for the first time last school year generated an excitement in the social studies that was unparalleled in my years as coordinator.

We are also encouraged by, and most grateful for, the steadfast bipartisan commitment of Congress to assist us in our endeavors. Through the Ellender Fellowship Program, we have been able to offer this educational opportunity to tens of thousands of teachers and students who otherwise would not have been able to participate.

Our community-based matching Fellowship Program allows us to engage the business community, philanthropic organizations, and others to form a truly unique partnership. Essentially, the federal dollars are the foundation upon which we build and we are proud of our ability to multiply these funds many times over. Last year, as the most important seed element of our work, the Ellender Fellowship Program constituted only 8 percent of our total funding picture and helped generate revenues of $20.8 million. During this current academic program year, the multiplier effect of Ellender Fellowships will be even greater.

Mr. Chairman, Close Up has always had a self-imposed mandate to make our programs available to students from all economic, academic, cultural, and geographic backgrounds. We have modified our program to serve the needs of special constituencies, such as limited-English proficiency students, students with physical impairments, at-risk students, and adjudicated youth. It is precisely these students, for whom special learning opportunities are seldom made available, who often benefit the most. In many instances, participation in Close Up makes a lifelong impression on these young people. A teacher from South San Francisco, California, explains:

> Because this is a small alternative school for potential "drop-outs", this program is especially meaningful. The opportunity for these students to attend the Close Up Program has allowed some of them to expand their interests and horizons of the future...it is a program quite superior in its entirety, and beyond comparison.

NEW AUTHORIZATION FOR ELLENDER FELLOWSHIP PROGRAM

Mr. Chairman, just last week, Congress reiterated its support of our work by extending the authorization of the Allen J. Ellender Fellowship Program and expanding its scope. We are most grateful for the opportunity to broaden our outreach and strengthen our focus with often neglected new constituencies. I have attached a summary of the conference agreement on H.R. 5 for your information.

The new authorization provides for the continuation of the Fellowship Program for students and teachers through 1993. Let me assure you, our work with students and their teachers has always been and will continue to remain our priority. Continued funding of this program will enable us to respond better to the demand for assistance from communities throughout the country, and to maintain our commitment to include the disadvantaged in all our programs.

The Close Up Foundation respectfully requests $2.8 million for FY'89 to help us involve more students of need and their teachers in our Washington Program. The increase in funding would be utilized primarily to continue our strong outreach into America's neglected constituencies through effective community and private sector partnerships.

Looking back on our appropriations from 1983-1988 (inclusively), some interesting statistics emerge. During this six-year period, the appropriation for the Ellender Fellowship Program increased 11.7 percent. At the same time, our tuition increased 22.5 percent (roughly equivalent to that of inflation) mostly as a result of increasing costs of room, board, and transportation in the Metropolitan Washington area. The number of participants increased by 33.5 percent, and the amount of community- and student-sponsored tuition dollars increased by 54.7 percent. Most importantly, our fellowship funding obligation, always successfully met, grew more than 100 percent. These figures illustrate the fact that the federal appropriation has remained relatively constant while Close Up has worked each year to expand its outreach to include more schools, more educators, and more students from low-income families. With increased seed monies from Congress, our work with disadvantaged and at-risk youth will be even more productive.

PROGRAM FOR OLDER AMERICANS

As I indicated earlier, Congress has acknowledged that there are other constituencies who will benefit greatly from participation in Close Up programs. The new authorization provides for economically disadvantaged senior citizens to be eligible for the Ellender Fellowship Program. For more than four years, Close Up has conducted an extremely well-received Program for Older Americans (POA). In fact, a number of our participants have returned for two years in a row. As one POA participant put it:

> My experience is one I wish I could duplicate for every senior citizen. We could see the need for our own involvement as we live out the last third of our lives. How to leave America better because we have been here is a real challenge.

We have observed the remarkable results of our Program for Older Americans. Volunteer networks have begun to be established throughout the country. Many of our POA alumni look upon their participation in Close Up as the launching of a second career. They have returned to their communities and have shared their enthusiasm with their peers. They have become involved as mentors and participants in many of our student activities and conducted intergenerational civic education programs. This ripple effect has been one of the most rewarding aspects of our work.

Almost each of our Program for Older American participants has a productive story to tell. Some results include:

- An alumna in Arkansas developed an eight-part government studies program titled "We the People" for her local community center.
- An alumnus from San Diego, California organized a bond issue referendum.
- Alumni have established weekly discussion groups on current political issues utilizing Close Up textbooks and have organized voter registration drives.

Close Up has worked diligently with a number of communities to help raise fellowships for disadvantaged POA participants. From our experience, those who have received financial assistance have been the most enthusiastic about participating and about contributing their talents as individuals on behalf of their own communities. As with everything we do, our desire is to offer this program to the broadest possible spectrum. Funding for this portion of the Ellender Fellowships will ensure participation of individuals of limited means. This broad-based representation will strengthen our overall program composition and increase the volunteer networks which have become so meaningful for communities throughout the country.

PROGRAM FOR NEW AMERICANS

The heavy influx of immigrants in recent years has altered dramatically the profile of student populations in many of America's communities and schools. Our country has always thrived on the diversity of its citizens, but, school districts throughout the United States are challenged as never before to meet the educational needs of newly-arrived immigrant students.

We have been consistently encouraged in discussions with educators in large and small cities all over the country to develop and implement a specially-designed civics education program to assist the recent immigrant populations. We have done so and are piloting a special program for students of recent immigrant families (Program for New Americans) which has the potential to contribute significantly to this important educational need in America.

The need for this program is reinforced by the recent passage of immigration reform legislation which requires that individuals seeking permanent residence and citizenship have adequate knowledge of history, government, and the English language. These citizenship skills are essential for access to America's mainstreams of opportunity.

The New Americans Program is designed for tenth and eleventh grade high school students from families who have recently immigrated to the United States. In this way participants will have a minimum of one year back in their classrooms and communities to share their learning experiences and new skills. The program is geared to those students, regardless of their country of origin, who have acquired at least a minimum proficiency in the English language, and who need greater understanding of American cultural and political traditions. Many, if not most, of these young people are considered at-risk students because of their high drop-out rate. Participants in this program will explore the democratic process in their home states and in Washington, D.C., through a three-part program.

Part I takes place in the students' own community and is intended to prepare them for the Close Up program in Washington, D.C. During their week in the nation's capital, Part II, students will explore the concepts underlying American democracy, ideas embodied in the U.S. Constitution, and the role of the federal system in our pluralistic society. Students will gain an understanding of and appreciation for the rights and responsibilities of American citizens. They will learn of the many contributions of Americans from diverse cultural and ethnic backgrounds. Part III encourages students and teachers to design and conduct, at the local level, school and community service projects similar to Close Up's local program activities.

Although the pilot program will be conducted the week of May 22, educators and officials have already recognized its potential. One associate superintendent stated:

> Many of these students' countries of origin are totalitarian societies. They need to understand the United States' constitutional heritage, democratic values, and commitment to the rule of law. They must know how our governmental institutions function and serve citizens.

REQUESTS FOR FISCAL YEAR 1989

Mr. Chairman, in addition to our request of $2.8 million for the student/teacher portion of the Ellender Fellowships, and as a result of the broadened authorization, we respectfully request $1.8 million for the two new components of the Fellowship Program. These monies will significantly help to establish the important seed element so vital in developing an effective fellowship partnership with civic groups and the private sector for our Program for Older Americans and Program for New Americans.

The Ellender Fellowship Program operates on a forward funding cycle in order that we know in advance how many students we can assist financially. Therefore, we would ask that, of these funds, $600,000 be made available for the period beginning on October 1, 1988 through June 30, 1989 to enable us to provide fellowships for these two new programs during our 1988/89 academic year. We ask that the remaining $1.2 million become available on July 1, 1989 as part of the normal forward funding cycle to be utilized during our 1989/90 academic year.

Mr. Chairman, these two programs, coupled with the ongoing student/teacher program represent an expanded commitment of the unique partnership that does so much to contribute to civic literacy and responsibility across the country. All of us at Close Up know only too well that our request to expand this precious seed element comes at a time of severe budgetary constraints. We can only offer to you and other members of the Subcommittee our record of accomplishment, the widespread and growing enthusiasm for our work, the recognized need for civic education assistance for so many of our at-risk and often neglected constituencies, and our unwavering commitment to multiply significantly these important and scarce resources. I thank you for the opportunity to present this testimony, for your strong support in years past, and for your consideration of this current request. I know that the thousands of teachers, students, senior citizens and New Americans who will have the opportunity to learn more about their government would also wish me to express their deep gratitude.

Again, thank you. I would be pleased to answer any questions that you or other members of the Subcommittee may have.

SUMMARY OF CONFERENCE AGREEMENT ON H.R. 5
ALLEN J. ELLENDER FELLOWSHIP PROGRAM

I. Extends the Allen J. Ellender Fellowship Program through 1993,

II. Authorizes the Close Up Foundation to carry out its "program of increasing understanding of the Federal Government among secondary school students, their teachers, and the communities they represent ("Subpart 1"),

III. Requires funds to be used for financial assistance to "economically disadvantaged students and their teachers",

IV. Requires that "every effort will be made to ensure the participation of students and teachers from rural and small town areas, as well as from urban areas" and that "special consideration will be given to the participation of students with special educational needs, including handicapped students...and ethnic minority students",

VI. Establishes new category of Ellender Fellowships for economically disadvantaged older Americans and recent immigrants ("Subpart 2"),

V. Requires that "every effort will be made to ensure the participation of older Americans and recent immigrants from rural and small town areas, as well as from urban areas" and that special consideration will be given to those with "special needs, including handicapped individuals and ethnic minorities",

VI. Authorizes $3 million for Subpart 1 for FY'89, and such sums as may be necessary for each of the following years, and

VII. Authorizes $2 million for Subpart 2 for FY'89, and such sums as may be necessary for each of the following years if Subpart 1 receives an appropriation of $2.5 million or current services level.

STATEMENT OF CHARLES A. WALKER, PH.D., CHANCELLOR, UNIVERSITY OF ARKANSAS AT PINE BLUFF

Mr. Chairman and members of the Subcommittee, I am very pleased to appear before you to discuss federal funding for student and institutional aid programs supported by your Subcommittee. These programs are vital to the continued existence and viability of our nation's educational systems. The Historically Black Colleges and Universities (HBCU) in this country, and the many bright students that attend these schools, rely heavily upon this support.

I serve as the Chancellor of the University of Arkansas at Pine Bluff (UAPB), one of the nation's 106 historically black colleges. In 1972, known before as Arkansas AM&N College, UAPB became a part of the University of Arkansas system. UAPB enjoys a past that is rich in tradition and anticipates a future that will equip students to meet the challenges of a technological era. The University's commitment to this philosophy is evident in the programs designed to strengthen areas of academic weakness to assure success in the pursuit of a degree, as well as programs that challenge students with strong academic backgrounds. Three academic divisions; Agriculture and Technology; Arts and Sciences; and Teacher Education, offer degree programs in nearly 50 areas, ranging from medical technology to recreation. A four year military science program prepares men and women for careers in the U.S. Army, if they desire. Pine Bluff, the home of UAPB, is the hub of a fast growing industrial and agricultural region, with a population of about 60,000 persons.

Of particular importance to our school is the support of the Title III, Part B programs within the Department of Education. Title III, Part B focuses on strengthening and support of Historically Black Colleges and Universities. Formula grants for HBCUs are designed to help improve their programs and management with the purpose of enhancing educational opportunities for their students. It is also intended to, on a long-term basis, facilitate a decrease in reliance on governmental financial support, and to encourage reliance on endowments, federal competitively gained resources, and private resources. The funding provided for this program by your Subcommittee is very critical to the continued development of UAPB as a recognized producer of promising graduates. The President's Title III FY 1989 budget proposal of $80.4 million is a substantial improvement over previous years. I urge your Subcommittee to give consideration to providing this level of funding.

Part C, Endowment Development grants of Title III are equally important to institutions which, like UAPB, make a substantial contribution to educational opportunities for minorities and the poor. Through a matching grant program to establish or increase endowment funds, Part C enables institutions to become more financially independent and enhance their developmental stability. UAPB continues to strive for financial independence and institutional stability, so I encourage your Subcommittee to provide adequate support for this program.

Student aid support such as Pell Grants, Guaranteed Student Loans, College Work Study, and Supplemental Educational Opportunity Grants are all vital to insuring educational opportunities for young, bright students. Student aid resources provided by your Subcommittee represent the genuine base of support that allow disadvantaged students to attend our schools.

Mr. Chairman, an area of great concern that I wish to bring to your attention is the serious decline in the number of Doctorate Degrees that are being awarded to blacks in this nation. A decline from an already low 600 to 350 was witnessed last year. We recommend that actions be taken to correct this problem, and that programs be established at recognized minority institutions to enhance their capability to strengthen graduate programs including Doctorate Degrees.

Finally, the University of Arkansas at Pine Bluff recommends the establishment of specific federal initiatives aimed at strengthening the technological and research infrastructures of educational institutions that offer degrees in the technological and engineering sciences. Such initiatives are particularly valuable and important in attempts to investigate technological challenges that face our nation's young scientists, scholars and clinicians.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to present the views of the University of Arkansas at Pine Bluff. I am pleased to respond to any questions you may have.

STATEMENT OF THE EXECUTIVE COMMITTEE OF THE COUNCIL OF ERIC DIRECTORS

This presentation is in support of the efforts of the Department of Education and its Office of Educational Research and Improvement (OERI) to make the ERIC information system more effective. In order to do this, OERI has developed several new initiatives, specifically: an expanded role for the ERIC Clearinghouses to reach new audiences, such as policy-makers, parents, students, and journalists; creation of new interactive relationships with other organizations identified as "ERIC Partners;" and establishment of a new unit within the ERIC system called ACCESS ERIC, which will be charged with systemwide marketing responsibilities. All of these efforts are enthusiastically endorsed by the Executive Committee of the Council of ERIC Directors. However, we do feel that OERI's appropriation request for ERIC underestimates the funds needed to adequately support its new initiatives, and does not take into consideration the years of underfunding.

FUNDING REALITIES

Table one dramatically displays the realities of funding for the ERIC system. Between 1969 and 1987 the funding for ERIC has decreased more than 60% in constant dollars. At the same time, however, ERIC's basic database activities have remained constant, with more than 30,000 new titles being added to the system in 1987 alone. While ERIC has been able to maintain a strong and viable database, many of its dissemination services, such as its synthesis publications and its ability to respond to users' requests, have been greatly diminished.

In order to meet the objectives articulated by OERI, ERIC will need a $12 million budget for FY 1989.

THE ERIC MISSION

What is ERIC's Mission? -- In RFP-88-005, the Office of Educational Research and Improvement (OERI) described the ERIC mission as follows:

> ...responsible for developing, maintaining, and improving access to the world's largest education literature database...
>
> ...a highly interactive network consisting of Central ERIC management staff within OERI; a network of clearinghouses, each responsible for a specific scope area; the ERIC Document Reproduction Service (EDRS); the ERIC Processing and Reference Facility; and public and private publishers and vendors of online and CD-ROM computer information retrieval services. New components will be added to the system, including ACCESS ERIC,... and ERIC Partners.

The ERIC Clearinghouses have the following responsibilities:

- They acquire specific education literature within their particular scope areas, giving priorities to the highest quality and most relevant materials;

- They process the selected items for entry into the database, including cataloging, indexing, and abstracting documents;
- They understand the critical issues in their field, and prepare materials for researchers, practitioners, and policy-makers that summarize the literature and identify state-of-art practices;
- They provide diverse users with products and services, such as brochures, digests, and training on the use of the ERIC database;
- They establish and carry out dissemination programs designed to bring ERIC-product materials to researchers, practitioners, journalists, policy-makers and others.

Has ERIC Been Successful? -- This question can be answered in two ways. First, statistically:

- Total acquisitions in the ERIC database (1966-1987) -- 636,713 titles
- Documents evaluated annually for possible addition to the ERIC database -- 35,000
- Inquiries/questions answered annually -- 118,000
- Estimated number of users of the ERIC system (annually) -- 2.7 million

The above figures, while impressive, do not tell the complete story of the respect awarded to ERIC in relation to other databases. Consider the testimony of Dr. Donald P. Ely at the OERI/ERIC Oversight Hearing conducted by the House Subcommittee on Select Education on July 30, 1987:

> ...commercial organizations that provide access to more than 300 databases list ERIC as one of the five most frequently used, with more than 50,000 hours of search time logged per year. In government, public libraries, and universities, ERIC is the most frequently used database...

This clearly indicates that the ERIC information system has been successful in providing a vital link between the research and development community and education practitioners, which is the role of dissemination. **Without this strong link between discoverers and users of new knowledge and new ways to make education more effective, our education system cannot improve or compete in the world marketplace.** While ERIC has been successful on the surface, its underpinnings have deteriorated through funding policy that one could easily liken to anorexia nervosa.

Specific Impact of Restricted Funding -- Three areas in particular demonstrate how the steady decrease in real funding has affected the ERIC system. These areas are: personnel, training, and technology. Lynn Barnett, Chair of the ERIC Technical Steering Committee, discussed these in her July 1987 statement to the House Subcommittee on Select Education. The personnel problem is summarized thus:

> Ten years of level funding have had a devastating impact on ERIC technical personnel....ERIC personnel have left in a steady stream in the past several years for positions in academe, government, the private sector, and even the nonprofit sector. Key staff have been lost by every Clearinghouse and the ERIC Facility.

Closely related to personnel issues is the training problem, which has both an internal and external significance. Ms. Barnett explained:

> Adequate training of technical personnel is crucial to the efficiency of a system like ERIC, since the tasks associated with database building, user services, and product development are extremely labor-intensive....Internally, ERIC technical staff have suffered from limitations on training opportunities. The Clearinghouse staff need two types of expertise: library/information science and their Clearinghouse's subject scope area. Attendance at professional meetings is crucial to staying abreast of both fields, yet there have been very few funds available to get to those meetings.

In addition, there is no question that current personnel will be called upon to provide training or technical assistance to ACCESS ERIC staff, but no additional funds have been allocated for that purpose.

Similarly, funding limitations have affected the ERIC system's ability to maintain technological currency. As the Technical Steering Committee statement pointed out,

> Since Clearinghouses are prohibited from purchasing equipment with contract funds, they either take what their host organizations provide or wait and hope for sufficient Department of Education funding to lease other equipment. However, sometimes the Clearinghouses do not have equipment that the ERIC user community already has in operation.

Anticipated Results of Increased Funding -- With an increase in ERIC's funding to $12 million, a number of specific improvements will be possible:

- increased training of ERIC end-users;
- wider development and distribution of theory-to-practice publications;
- sufficient placement of computers and related equipment for improved system efficiency and responsiveness;
- broader development of ERIC Partners, who serve as ERIC multipliers; and
- improved system staffing for responding to requests.

It should be clearly noted that the federal support of ERIC is only a fraction of the total dollars used to bring this information system to the education community. Currently it is estimated that for every federal dollar spent, there are four dollars spent by libraries, resource centers, state and local education agencies, etc. to make ERIC available to their clients and educators. An increase in ERIC's funding will leverage this non-federal support even further.

CONCLUSIONS

There is a certain irony in the underfunding of ERIC. OERI conducted a redesign study of ERIC because it felt that there were problems in the system. The ERIC Redesign Study Group accurately identified many areas where ERIC could more comprehensively serve the American education public. To improve the system, OERI has assigned additional activities to the Clearinghouses and is developing the new unit, ACCESS ERIC, to promote the system and thereby to create greater use and demand for ERIC's products and services. Additional responsibilities and increased user demand should be accompanied by proportionately higher funds, but the OERI budget request, although larger than last year, is not sufficient. If the increase in user demand is not met by adequate staffing and services, user dissatisfaction will increase, and ERIC will again be seen as being unresponsive. We may be programmed for failure. This vicious cycle must be stopped.

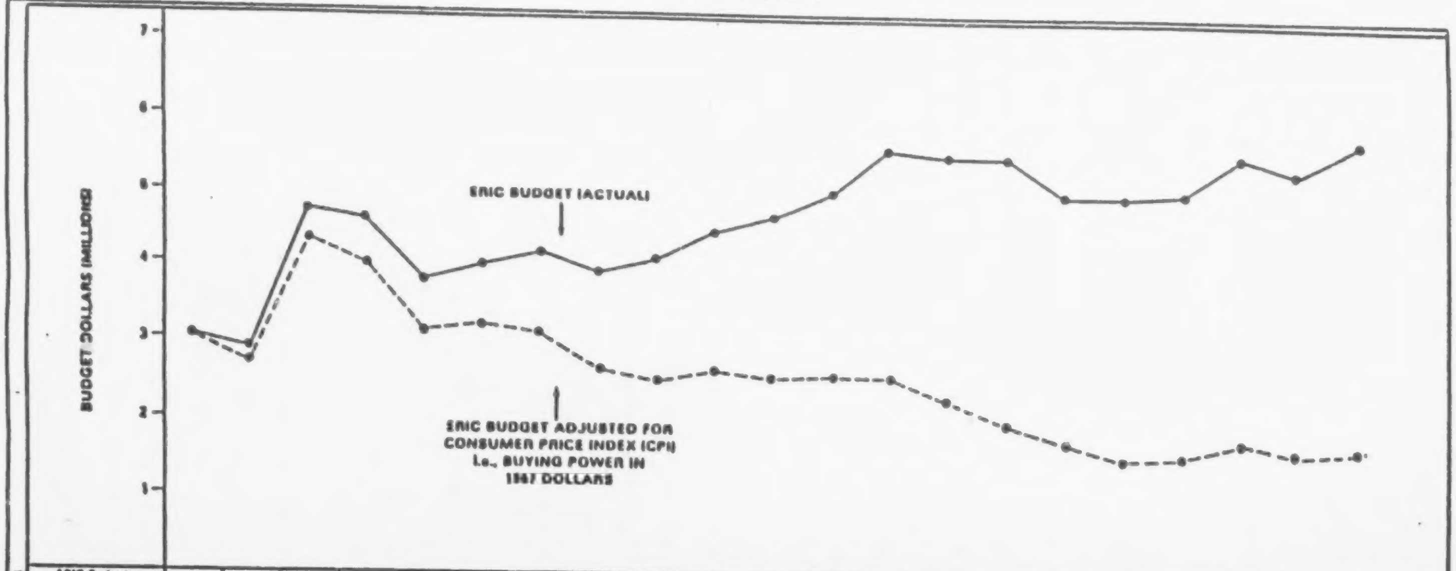
Therefore, the Executive Committee of the Council of ERIC Directors proposes the following legislative language for the ERIC appropriation:

> **For necessary expenses to maintain and expand the nation's Educational Resources Information Center (ERIC) program, a minimum of $12 million will be appropriated to underwrite the entire system. The appropriation will support the several existing and proposed system components as follows: (1) approximately 80% shall be designated for the operation of the sixteen (16) ERIC Clearinghouses (set forth in Section 405 (G)(1)(c) of the Higher Education Technical Amendments Act of 1987); (2) approximately 10% shall be set aside for the operation of systemwide technical, reference, and in production support units; and (3) approximately 10% shall be designated for the establishment and operation of a proposed systemwide dissemination and outreach unit known as ACCESS ERIC and for other proposed system innovations.**

It should be clear that ERIC has been grossly underfunded and that it can adequately respond to traditional expectations and the new OERI initiatives only with additional financial support. ERIC is a proven success that for more than 20 years has linked millions of concerned Americans to the education literature. Congress and the Administration both have a responsibility and obligation to maintain the viability of this dissemination system so vital to the success and improvement of our schools. We urge this Committee to recommend the additional funding for ERIC so it can reach its true potential as it enters its third decade of service to American education.

TABLE 1

ERIC BUDGETS (ANNUAL)
ADJUSTED FOR CONSUMER PRICE INDEX (CPI)
INFLATION



THOUSANDS

YEAR	1967	1968	1969	1970	1971	1972	1973	1974	1975	1976	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986	1987	1988
ERIC Budget (Actual)	3057	2896	4750	4626	3816	3994	4167	3865	4074	4477③	4650	5035	5600④	5500	5500	4925	4926	5070	5600	5378⑥	5857	
ERIC Budget ⑤ (Adjusted for Inflation)	3057	2779	4326②	3978	3146	3187	3123	2616	2527	2626	2562	2578	2576	2229	2019	1695	1669	1630	1738	1627	1716	
Consumer Price Index (CPI)	100	104.2	109.8	116.3	121.3	125.3	133.1	147.7	161.2	170.8	181.5	195.3	217.4	246.8	272.4	289.1	298.4	311.1	322.2	328.4	341.5①	

① Projection Based on Estimated 4% Inflation

② Major New Work Added — CIJE Abstract Journal

③ All Volume of Documents Handled 61% Larger than in 1970

④ "Wedge" Period at Government Fiscal Year Change Omitted From Year Total

⑤ Buying Power in 1967 Dollars

⑥ Gramm-Rudman Mandated Reduction

STATEMENT OF THE COUNCIL ON LEGAL EDUCATION OPPORTUNITY

On behalf of the Council on Legal Education Opportunity (CLEO), I submit this testimony regarding the appropriation of Assistance for Training in the Legal Profession, Title IX, Part D of the Higher Education Act of 1965, as amended, pursuant to which CLEO undertakes activities to assist individuals from disadvantaged backgrounds to obtain a legal education.

CLEO has been in operation since 1968. It was formed as a joint effort by the Association of American Law Schools (AALS), the American Bar Association (ABA), the National Bar Association (NBA), and the Law School Admission Council (LSAC), and in 1972 La Raza National Lawyers' Association (now the Hispanic National Bar Association (HNBA)) joined as a sponsoring organization. CLEO's programs were designed and continue to serve those educationally and economically disadvantaged persons who have had limited access to a legal education. While there is evidence that access to legal education has increased since 1968, in contrast to previous levels, access to graduate and professional opportunity by disadvantaged Americans continues to be an elusive goal. The goal of greater economic and political participation in the mainstream of society remains an unrealized dream for many: For example, the 1982 Annual Survey on Current Population Statistics of the Bureau of Census reports that of 606,000 lawyers in the United States, only 3.6% were members of a minority group. Currently, this percentage has increased to just over 4% of the more than 650,000 lawyers nationally.

The effort toward meaningful economic and political participation of minorities has been diligently pursued in higher education for very cogent reasons: higher education has proven to be a more effective vehicle than most for obtaining a more equitable distribution of political influence, simply because those persons most involved in the decision-making process of this country, are, themselves, products of the higher education system. This phenomenon is particularly germane to the legal profession given its role within the country's decision-making process generally and its historic lack of accessibility to minorities. The profession's impact on the formation of national policy is widely conceded because of the relationship of lawyers to all three branches of government, comprising almost exclusively the Judicial, and significant percentages of both the Legislative and Executive. It is this unique role played by the legal profession that raises compelling reasons for a continued emphasis on increasing the number of minority attorneys.

During the 1967-68 academic year, reliable statistics indicated the number of minority students enrolled in law school was as follows:

Blacks	1,245
Mexican American	180
Puerto Rican	69
Other Hispano Americans	81
American Indians	32
Total Minority Students Enrolled in Law School:	1,607

While these numbers have improved significantly with regard to the 1986-1987 academic year as reflected in the Survey of Minority Group Students Enrolled in J.D. Programs in Approved Law Schools, 1986-87[1], there was a decline in the number of Black and Mexican American law students from 1986-87, as follows:

	1985-86	1986-87
Black American	6,051.5	5,894
Mexican American	1,635	1,512
Puerto Rican	412	471
Other Hispano Americans	1,632	1,882
American Indian or Alaskan Native	462.5	488
Asian or Pacific Islander	2,153	2,303
Total Minority:	12,346	12,550

Furthermore, with respect to total enrollment in U.S. ABA-approved law schools, which was 123,277 in 1986-87, Black students never exceeded the 4.6% of total enrollment they registered in 1976-77. Hence, not only are Puerto Rican, American Indian, and other minority groups still underrepresented in law schools, but the proportion in total law school enrollment of minorities, especially Blacks and Mexican-Americans, is declining.

When one considers the fact that between 1963 and 1985 the number of students in law school went from 46,666 to 118,700 and that the number of minority students enrolled in law schools has stabilized at 9% over the last five years, there is little doubt that the disparity which served as a catalyst for CLEO's inception in 1968, as yet, has not been sufficiently ameliorated to warrant the termination of the CLEO program.

The CLEO program works to increase the number of disadvantaged persons within the legal profession by providing an alternate mechanism for assessing, within the law school environment itself, the potential of each program participant for the study of law. Thus, the program is designed to serve those persons who aspire and are qualified to enter the legal profession but who may be unable to gain admission to law school through the traditional admission process.

The program achieves its goal of identifying qualified law school candidates and providing the opportunity for law school matriculation via pre-law academic summer institutes for prospective law students and the provision of annual fellowships.

The academic component of the Institutes is administered by seven (7) law schools located across the country,[2] sponsored jointly by CLEO and regional consortia of ABA-accredited law schools. The Institutes are based upon the premise that significant numbers of economically and educationally disadvantaged students can be identified and prepared to successfully negotiate the law school curriculum. The Institutes mirror the law school experience by providing a six-week intensive study program in legal analysis and law development and emphasize abstract thinking, legal research and legal writing techniques. The Institutes are staffed by regular law faculty whose primary responsibility during the Institute is to evaluate each student's potential for successfully mastering the law school curriculum. Students who successfully demonstrate this potential are provided law school placement assistance and an annual stipend.

The CLEO Summer Institutes have been highly successful. To date, CLEO has helped 4,595 economically and educationally disadvantaged students to entar 160 accredited law schools throughout the country. Nearly 4,052 of these students have already graduated from law school and are now actively pursuing their careers in public service organizations, private law firms, government agencies and private industry.

CLEO has witnessed an overwhelming response to its program through the yearly number of applicants, and it is expected that this trend will continue. Last year (1986-87), one thousand, four-hundred thirty(1,430) students applied for 200 openings in the program, which attests to the continued credibility and viability of CLEO. The total applicant pool for 1988 is currently above eighteen-hundred (1,800), an increase of 400 applicants over 1987.

Data clearly demonstrates that CLEO Fellows have attained an impressive record of achievement by any measure, including performance within the academic arena of law school, bar performance, and most importantly, the employment activities of the program's graduates. The program has produced approximately 4,052 law school graduates involved in a broad spectrum of legal and law-related activities, including lawyers (public interest, private, corporate); judges; state representatives; law professors; executive administrators in various fields; Congressional staff, etc. The net result of the program has been increased access to the legal system and to the decision-making machinery of the country by those who have been disenfranchised for reason of race and/or economic status. Thus, the CLEO model of academic and financial support is one that works.

The continued success of the Summer Institutes, however, has been, to an increasing degree, dependent upon the generosity and largess of the law school community. Although authorization ceilings for the program have been set at $10 million dollars in previous years, the Legal Training for the Disadvantaged Program received only one million dollars in appropriations since 1974; in Fiscal year 1985, the appropriation was modestly raised to $1.5 million dollars. This appropriation ceiling, in conjunction with the Gramm-Rudman-Hollings cutbacks in 1986, has limited the number of students that can be accommodated by the program and has placed a greater burden on participating law schools to cover increasing institute, tuition and living costs from their own financial resources.

Initially, the non-federal share represented between 30-40% of the total institute costs. However, over the last several years, the ever-spiralling costs of goods and services coupled with the effects of inflation, have thrust an even greater share of the Institutes' operating costs upon the law school. Given the fixed level of federal support, the law school community now absorbs approximately 60-70% of institute costs, as a demonstration of their commitment to the program. The law schools, without more federal assistance, cannot continue to maintain the academic institutes, while themselves facing reduced education budgets.

In addition, the law schools are asked to provide tuition scholarships, as well as other forms of financial support in recognition of the economic needs of the students served by the program. At a time when legal education is, itself, in a difficult fiscal situation, it is extremely important to realize that $1.9 million of annual federal support for this program generates over $3,000,000 in cash and services annually from the law schools. It is unlikely that these funds will continue to be forthcoming without the catalyst provided by the Legal Training for the Disadvantaged Program through CLEO.

Also, the ABA has for years been a principal contributor to the program in its dual capacity as one of CLEO's sponsoring organizations and administrative conduit for the funding from the federal government. The ABA contributes annually some $40,000 to the program's operation to address unanticipated financial obligations unmet by any other funding source. Additionally, CLEO has received in-kind support from the Law School Admission Council (LSAC) to cover administrative costs of the program.

The financial component of the program is provided by way of annual fellowships. The provision of the stipend is contingent upon the satisfaction of several conditions: full-time enrollment at an ABA-accredited law school in the fall term immediately following participation in a Summer Institute, and the maintenance of academic "good standing" status throughout the duration of the grant. For the 1988 fiscal year, almost $1,220,400 will be provided by CLEO to disadvantaged students enrolled in law schools.

Research shows that financial aid is an important factor in college choice and persistence, particularly when a student's socio-economic background is taken into consideration. Students from lower socio-economic backgrounds tend to be more concerned with tuition costs and other practical considerations than students from more affluent backgrounds. There is also less liklihood that students will withdraw if they come from more affluent rather than lower socio-economic backgrounds.[3]

Out of a total of 1,430 students who applied to the CLEO Program in 1987, 632 of these were financially eligible; that is, they met the financial criteria that CLEO imposes, using the Federal Poverty Guidelines. The result in 1980 was that 60% of students qualified financially for the program. As CLEO has 210 (now 252) available spaces in it's program each year, only 33% of the financially eligible students were selected to participate in the program.

Using a personal gross income range of $4,000 to $15,001 and over, nearly half of the 1987 CLEO participants were in the $4,000 or less gross income category.

Applying the same criteria to family income, the highest number of CLEO 1987 participants earned $4,000 or less.

Average charges to students for college tuition and fees are up 5 to 8 percent for academic year 1987-88, outstripping inflation for the seventh consecutive year, according to survey data released by the College Board. The general cost of living, as measured by the Labor Department's consumer price index, rose 3.7 percent in the last year, although recent price increases have reached an annual rate of more than 5 percent.[4]

Tuition and fees for public and private institutions increased 6 and 8 percent, respectively, over 1986-87. The average charges for on-campus room and board rose 4 percent at public colleges and 6 percent at private colleges.[5]

Average total costs for students living on campus are just under $12,000 this year, with the most expensive schools just shy of $20,000.[6]

Cost of Law School Tuition, 1985-86:

	Median:	Average:
Public	$1,998.	$2,135.
Private	$8,042.	$8,286.

With the full cost (including room, board and tuition) for a student attending most law schools hovering around $10,000, the CLEO stipend, which was increased in 1988 from $1,750 and $1,600 for first year students and upper classes to $2,220 and $2,000 respectively, is well below the awards available from other graduate programs funded under Title IX. The total amount that a graduate/law student may borrow under the Graduate Student Loan Program is $25,000, which includes any loans made at the undergraduate level. The ALAS and PLUS loan programs allow graduate students to borrow $3,000 per year for a total of $15,000, and NDSL provides loans of $4,000 per year to a maximum of $12,000 for the combined undergraduate/graduate program of study.

The stipends, while inadequate, do provide a minimum of support for the needy students which the program services. Yet, even these amounts cannot be sustained in future years without additional appropriation. Other federally-funded graduate and professional programs, e.g., GPOP, Public Service and Mining Fellowships, have provided stipend assistance of approximately $6,000 per year and some have had institutional support components as well. This disparity in funding levels for students funded through similar federal programs under the same legislation has substantially hampered CLEO's ability to recruit students who would otherwise like to pursue a legal education. It was to correct this disparity in assistance, coupled with the program's impressive record of achievement, that encouraged Congress in 1980 to amend the Legal Training for the Disadvantaged Program legislation to provide new appropriation ceilings under the reauthorized Higher Education Act of 1965, as Amended.

The Program is cost-effective. While many programs have suffered substantial cost increases over the years, CLEO has been a rare exception. In the last eight (8) years, the program has continued to service successfully its disadvantaged student population with only modest increase in cost to the federal government. Judicious cost-saving measures have been implemented over the past several years with an eye toward fiscal austerity, including executive staff salary freezes and significant reduction in program staff; once staffed by eleven employees, the program now operates with a staff of seven. A careful review of the program's budget already reveals a "bare-bones" operation.

The federal government has made a major commitment in the last decade to increasing educational opportunities for the poor and disadvantaged groups within society. This is an important commitment not only in terms of fairness, but also in terms of wise allocation of resources. Compared to many federal support programs, CLEO is impressive because the payoff is concrete, clear and quick. The modest federal support is matched several times by the substantial voluntary contributions of the law school community and is repaid to the government many times over in higher taxes from these individuals and in their service to society.

Observing the demonstrated success of CLEO participants and the continued support and cooperation of the nation's law schools, we request that you appropriate funds to legal training for the disadvantaged at the level of $2 million for FY 1989. This amount would permit CLEO to immediately increase student awards to approximately $2,200 for all three years of law school; even this level of support would not achieve parity for the program with grants being given by other Title IX programs.

In many ways, CLEO serves as a model of financial integrity. It is also an outstanding example of government partnership with the private sector in furtherance of significant social goals. For these reasons, the CLEO program merits on-going support to continue its important and highly successful work.

Thank you for your time and consideration.

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[1] A Review of Legal Education in the United States, Fall 1986, Law Schools and Bar Admissions Requirements, (American Bar Association, 1986). Reproduced by permission of the American Bar Association, 1987.

[2] The host law schools in 1987 were: the University of San Diego; University of Arizona; University of Missouri-Columbia; Ohio State University; Emory University; the University of Connecticut; and, Georgetown University.

[3] Noel, Levitz, Saluri and Associates, Increasing Student Retention, Jossey-Bass Publishers (1985), p. 205.

[4] "Black Issues in Higher Education", September 1, 1987, v. 4, no. 12, p. 3.

[5] Ibid.

[6] Ibid.

LETTER FROM FRED J. TAYLOR, CHANCELLOR, UNIVERSITY OF ARKANSAS AT MONTICELLO

May 10, 1988

Honorable William Natcher, Chairman
Labor-Health & Human Services-Education Subcommittee
Room 186/Dirksen Senate Office Building
Washington, DC 20510

Mr. Chairman:

I am requesting that your committee do whatever is necessary to provide an adequate level of funding which Title IIIA has received in the past. Title III programs in the four-year schools are now facing a sharp reduction in funding for 1988-89.

The reason for this action is required by Section 360(c) (1) and (d) of the Higher Education Act, Title III, as amended in 1986, which states that a specific portion of the appropriated funds from the Part A, Strengthening Program, must be reserved for two-year colleges. When appropriations are not increased, the four-year colleges and universities suffer the greater loss of funds.

The two-year college reservation of funds for 1988-89 is $51,001,316. When this amount is subtracted from the 1988-89 appropriation, only slightly more than $9.0 million remains to support the current four-year non-competing continuation grantees.

In February 1988, the University of Arkansas at Monticello (UAM) received a .998 percent funding approval for the 1988-89 non-competing continuation grant (NCC) under the Strengthening Institutions Programs. Budget revisions and operational plans were initiated immediately. In March 1988, UAM received the disconcerting news that the 1988-89 budget will have to be ratably reduced. Rumors indicate that this reduction could be as high as 40 percent. If UAM's original approved Title IIIA Budget, in the amount of $372,788, is reduced to $223,673, it is apparent what will happen to the Plan of Operations for 1988-89 while trying to cope with a $149,115 reduction.

If this situation should occur, drastic measures will have to be taken to the extent of rendering the local 1988-89 program ineffective. After making the necessary major adjustments in each activity established educational goals and objectives could not be met. It is imperative that corrective action be taken which will be fair to all institutions of higher learning.

I urge you and your colleagues to exercise your expertise and influence to see that fairness prevails. Your help will be greatly appreciated.

Sincerely,

Fred J. Taylor

Fred J. Taylor
Chancellor

STATEMENT OF THE COUNCIL OF THE GREAT CITY SCHOOLS

Mr Chairman, my name is Michael Casserly and I am the Associate Director of the Council of the Great City Schools. I am pleased to have this opportunity to testify before this crucial Subcommittee on FY89 federal appropriations for elementary and secondary education programs.

Currently in its 32nd year, the Council of the Great City Schools is a national organization comprised of 45 of the nation's largest inner-city public school systems. Our Board of Directors is comprised of the Superintendent and one Board of Education member from each city, making the Council the only education group so constituted and the only one whose membership and purpose is solely urban.

The Council's membership serves nearly five million urban youngsters, or approximately 11.5 percent of the nation's public school enrollment. About one-third of the nation's Black children, 27% of the Hispanic children and 20% of the nation's Asian children are being educated in our schools. Almost one-third of enrollments are of children residing in families receiving public assistance, and nearly 75% of our average district's enrollment is minority.

Mr. Chairman, I would like to devote my brief statement this morning to a review of recent trends in federal spending on elementary and secondary education, and to a short series of recommendations for the current FY89 budget cycle.

We are pleased to note, Mr. Chairman, that the Department of Education proposed an FY89 budget that called for modest increases in the area of elementary and secondary education. While we are pleased, we are not gleeful. Since FY80, the federal government's financial commitment to elementary and secondary education has slipped rather badly.

For every $100 the federal goverment spent for all its functions in FY80, $1.10 of it was devoted to elementary and secondary. For every $100 the Administration proposed to spend in FY89, however, only 79 of it would go for elementary and secondary education. This drop represents an overall decline in federal spending effort of about 28% since FY80. Had the Administration maintained the same level of effort as in FY80, then its FY89 request for elementary and secondary education would have been about $13.6 billion rather than $9.5 billion.

We are genuinely pleased about two things, however. The first involves the increases that the Chairman has pushed for education in the last two budget cycles. Funds for elementary and secondary education have increased about 23.5% or $1.8 billion since FY86 -- or approximately eight times all cumulative increases realized between FY80 and FY86. Moreover, the FY89 budget picture would appear to allow additional new funds for elementary and secondary education this cycle.

The second item we are pleased about, Mr. Chairman, is H.R.5, the Augustus Hawkins/Stafford Elementary and Secondary School Improvement Amendments, and the opportunities it presents to this Committee for enhancing the education of our nation's children. The authorizing committees have done a tremendous job of recasting and improving the full array of elementary and secondary education programs by targeting the funds on areas of greatest need, enhancing parent involvement and accountibility, streamlining administration, and adding new local flexibility. To help realize the full potential for that new legislation, we would like to make a series of funding recommendations for FY89:

Recommendations

1. The Council of Great City Schools would recommend boosting total funding for elementary and secondary education programs by about $1.3 billion or approximately 14%. This increase would provide less than half the amount needed to bring the federal financial effort to a level comparable to that in FY80. Nearly $4.3 billion in increases would be needed to accomplish that task, but the requested amount would underscore recent Congressional commitment to education.

2. The Council would also recommend that approximately half of the FY89 increases in elementary and secondary education be devoted to the Chapter 1 program. In this case, we would propose that Chapter 1 be increased by $594 million or 13.7% in FY89. The Council would recommend that funding for the basic program be allowed to grow $154 million, enough to cover inflation at 4%. In addition, we would request that the Committee provide $30 million to improve access for private school students to Chapter 1 programs that were curtailed by the Supreme Court's Aguilar v. Felton decision. Finally, Mr. Chairman, the Council of Great City Schools would recommend that the authorizing language on concentration grants stand and that the full $400 million be triggered as authorized.

The Great City Schools worked tirelessly during the reauthorization process to devise a Chapter 1 concentration formula that balanced the legitimate and equal needs of our poorest inner-cities and rural areas. We believe that this balance has been achieved finally, and would thank the Chairman for the work he has devoted to this crucial area.

3. The Council would also propose that the funding for the Magnet Schools Assistance program be doubled in FY89 to $150 million. FY89 will commence the first year of this very popular and effective program's third funding cycle. Nearly 125 LEA's have applied for a total of $250 million in magnet aid in each of the first two cycles, but funding was sufficient for only 44 grants in the first cycle and 38 in the second. The authorization ceiling has now been lifted to accomodate this proposal, and the program has been retooled to give new priority for LEAs who have remained unfunded for at least one cycle (like Boston, Cleveland, Los Angeles) while protecting LEAs who currently have funds (like Prince George's County, Louisville and Buffalo). This program enjoys enormous popularity at the local level, and continues to have strong political backing in the Congress from a wide spectrum of members.

4. The Council of Great City Schools would also recommend to the Committee that $50 million be provided in FY89 to fund the Dropout Prevention demonstration grants authorized in H.R.5. The importance of this effort is hard to overstate. The nation's high school dropout rate remains perilously high. The highly touted education reform movement has not made a dent in the problem, and some would claim that it has made the dropout situation worse. It is clearly in the national interest to address this problem.

5. In addition, the Council would urge the Committee to consider funding for the new Even Start and Secondary Schools authorizations in H.R.5. Both programs are aimed at expanding the age ranges served by the Chapter 1 program into the pre-K and high school levels. In FY90, the secondary school program and the dropout prevention demonstration grants will transition into a single formula grant effort that we hope the Committee will be receptive to. Funding for the FY89 authorizations will help expand the benefits of Chapter 1, and through pre-school programs, work to prevent achievement difficulties that can be addressed early.

6. Finally, Mr. Chairman, the Council would urge the Committee to consider FY89 increases for PL94-142 and its early childhood counterpart, vocational education

basic grants, refugee and immigrant education, Impact Aid B's, drug free schools, and math and science education. The contributions that these programs and the areas already discussed are making to the achievement levels of our nation's school children are substantial indeed.

Mr. Chairman, again we would like to thank you for your commitment to elementary and secondary education. The work that this Committee is doing is having a measurable effect on the education of our young people. That concludes my testimony. I would be happy to answer any questions.

Thank you very much.

Summary of CGCS FY89 Appropriations Proposals
(in 000's)

Program	Final FY88	President's Request FY89	CGCS Request FY89
Grants for Disadvantaged			
Chapter 1, LEA	$ 3,829,600	$ 3,906,151	$ 3,982,784
Concentration Grants	0	154,000	400,000
Private School Access	0	0	30,000
Total Proposed Increase	$ 3,829,600	$ 4,060,151	$ 4,412,784
Impact Aid A's	$ 536,144	$ 547,000	$ 545,000
Impact Aid B's	134,036	0	150,000
Other	38,296	45,000	40,000
Total Proposed Increase	$ 708,476	$ 575,000	$ 735,000
Bilingual Education	$ 146,573	$ 156,573	$ 160,000
Emergency Immigration	28,722	28,722	50,000
Refugee Education	15,209	15,209	25,000
Total Proposed Increase	$ 190,504	$ 200,504	$ 235,000
Vocational Education			
Basic Grants	$ 804,216	$ 848,333	$ 850,000
Total Proposed Increase	$ 804,216	$ 848,333	$ 850,000
Adult Education	$ 134,036	$ 150,000	$ 150,000
Handicapped Education			
State Grants	$ 1,431,737	$ 1,474,239	$ 1,600,000
PreSchool Inc.	201,054	205,075	250,000
Early Intervention	67,018	68,358	75,000
Special Purpose	169,210	169,210	173,900
Total Proposed Increase	$ 1,869,019	$ 1,916,882	$ 2,098,900
Other Programs			
Even Start	$ 0	$ 0	$ 50,000
Drug Free Schools	229,776	250,000	250,000
Magnet Schools	71,805	115,000	150,000
Math & Science Education	119,675	119,675	200,000
L. E. A.D.	8,222	4,358	10,000
Dropout Prevention	23,935	23,935	50,000
Secondary Schools Imp.	0	0	100,000

STATEMENT OF MARTIN C. JISCHKE, CHANCELLOR, UNIVERSITY OF MISSOURI, ROLLA

MR. CHAIRMAN AND MEMBERS OF THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON COMMERCE, JUSTICE, STATE, THE JUDICIARY AND RELATED AGENCIES, MY NAME IS MARTIN C. JISCHKE, I AM A RESIDENT OF ROLLA, MISSOURI, AND I HAVE THE HONOR OF SERVING AS CHANCELLOR OF THE UNIVERSITY OF MISSOURI-ROLLA--ONE OF THE NATION'S LEADING TECHNOLOGICAL UNIVERSITIES.

I WOULD LIKE TO THANK YOU FOR THIS OPPORTUNITY TO TESTIFY ON BEHALF OF THE APPROPRIATIONS FOR THE NEW CENTERS FOR THE TRANSFER OF MANUFACTURING TECHNOLOGY PROGRAM OF THE NATIONAL BUREAU OF STANDARDS--APPROPRIATIONS WHICH ARE PART OF THE SUBCOMMITTEE'S 1989 BILL.

THE UNIVERSITY OF MISSOURI-ROLLA RANKS NINTH IN THE ENTIRE UNITED STATES IN THE NUMBER OF BACCALAUREATE ENGINEERS GRADUATED. OUR CAMPUS IS WIDELY RECOGNIZED FOR THE STRENGTH OF OUR ENGINEERING AND SCIENCE PROGRAMS INCLUDING THE AREA OF MANUFACTURING ENGINEERING. AMONG MY PROFESSIONAL ACTIVITIES AS AN ENGINEER AND AN EDUCATOR, I SERVE ON THE BOARD OF THE MISSOURI CORPORATION FOR SCIENCE AND TECHNOLOGY WHICH SEEKS TO FOSTER TECHNOLOGICALLY INTENSIVE ECONOMIC DEVELOPMENT IN OUR STATE.

MISSOURI IS ONE OF THE NATION'S LEADING MANUFACTURING STATES--WE RANK 16TH AMONG THE STATES IN THE VALUE OF MANUFACTURED GOODS SHIPPED AND 17TH IN THE NUMBER OF MANUFACTURING JOBS. THUS WE HAVE A VITAL INTEREST IN THE WELL-BEING OF THE MANUFACTURING SECTOR OF OUR ECONOMY.

I APPEAR BEFORE YOU TODAY TO URGE THIS SUBCOMMITTEE TO FUND $42 MILLION FOR CENTERS FOR THE TRANSFER OF MANUFACTURING TECHNOLOGY.
IT IS IMPERATIVE TO THE FUTURE OF OUR ECONOMY THAT THE UNITED STATES REGAIN PREEMINENCE IN MANUFACTURING. THESE CENTERS FOR THE TRANSFER OF MANUFACTURING TECHNOLOGY ARE A VITAL AND ESSENTIAL COMPONENT TO THE NATION'S EFFORTS TO ACHIEVE THIS GOAL.

MANUFACTURING IS AND WILL REMAIN A MAJOR COMPONENT OF OUR ECONOMY. TODAY, THERE ARE NEARLY TWENTY MILLION MANUFACTURING WORKERS IN THE UNITED STATES, REPRESENTING ROUGHLY ONE OUT OF FIVE JOBS. THE BUREAU OF LABOR STATISTICS HAS PROJECTED THAT THIS LEVEL OF EMPLOYMENT IN MANUFACTURING WILL CONTINUE AND PERHAPS GROW SLIGHTLY THROUGH THE MIDDLE OF THE NEXT DECADE. EVEN IF, AS OTHERS HAVE PREDICTED, AUTOMATION WILL--INDEED, MUST--REDUCE THE NUMBER OF MANUFACTURING JOBS IN THE FUTURE, THERE WILL REMAIN MILLIONS OF MANUFACTURING WORKERS IN THIS COUNTRY AND WE MUST REMAIN COMPETITIVE IN MANUFACTURING IF WE ARE TO

SUSTAIN THIS PIVOTAL PART OF OUR ECONOMY. BUT THE EVIDENCE ON AMERICAN MANUFACTURING COMPETITIVENESS IS NOT REASSURING. SINCE 1980 WHEN THE UNITED STATES HAD A SMALL POSITIVE BALANCE OF TRADE IN MANUFACTURING, LARGELY BECAUSE OF THE HIGH TECH PORTION OF THE INDUSTRY, OUR POSITION HAS DETERIORATED RAPIDLY.

IN 1986, OUR BALANCE OF TRADE IN MANUFACTURED GOODS WAS OVER $140 BILLION IN DEFICIT. THIS TREND CANNOT CONTINUE WITHOUT DISASTROUS CONSEQUENCES FOR OUR NATION'S ECONOMY AND SECURITY. OUR COMPETITORS ARE IMPROVING THEIR MANUFACTURING PRODUCTIVITY MORE RAPIDLY THAN THE UNITED STATES, THEY ARE INVESTING MORE IN MANUFACTURING RESEARCH AND DEVELOPMENT, AND THEY ARE MAKING BETTER USE OF THE NEW MANUFACTURING TECHNOLOGY THAT HAS BECOME AVAILABLE.

IT IS IMPORTANT TO RECOGNIZE THE DECISIVE ROLE THAT SMALL- TO MEDIUM-SIZED COMPANIES PLAY IN MANUFACTURING. FOR EXAMPLE, THERE ARE 7,400 MANUFACTURERS IN MISSOURI EMPLOYING 430,000 WORKERS. THUS, THE AVERAGE COMPANY EMPLOYS LESS THAN SIXTY PEOPLE. MANY OF THESE SMALL BUSINESSES SUPPLY OTHERS WHO ASSEMBLE PARTS TO FORM FINISHED PRODUCTS SUCH AS AUTOMOBILES, AIRPLANES, AND ELECTRONIC GOODS.

THE TYPICAL MANUFACTURER DOES NOT HAVE A RESEARCH AND DEVELOPMENT STAFF AND THEREFORE IS LIMITED IN ITS ABILITY TO KEEP ABREAST OF THE LATEST TECHNOLOGICAL

DEVELOPMENTS. AND THE NEW AUTOMATION TECHNOLOGY, PARTICULARLY THE FLEXIBLE MANUFACTURING SYSTEMS, OFFERS THE GREATEST OPPORTUNITY IN SMALL- TO MEDIUM-SIZED COMPANIES WHERE THE EFFICIENT SCALE OF OPERATIONS INVOLVES AS FEW AS SIX MACHINES AND LESS THAN SIX WORKERS. THE KEYS ARE THE PROPER SELECTION OF EQUIPMENT AND THE COMPETENCE OF A SMALL GROUP OF WORKERS.

THIS IS WHERE THE CENTERS FOR THE TRANSFER OF MANUFACTURING TECHNOLOGY CAN PLAY A DECISIVE ROLE. THE TYPICAL SMALL MANUFACTURER DOES NOT HAVE THE PEOPLE OR THE RESOURCES TO DEVELOP THE TECHNOLOGY OR TO COME TO WASHINGTON TO THE NBS'S AUTOMATED MANUFACTURING RESEARCH FACILITY TO ASSESS THE TECHNOLOGY.

THE TECHNOLOGY, INCLUDING THE ORGANIZATIONAL AND MANAGEMENT CONCEPTS NEEDED TO EXPLOIT THE TECHNOLOGY, MUST BE TAKEN TO THE MANUFACTURERS IN EVERY REGION OF THE COUNTRY. WE MUST EXTEND A HELPING HAND, IN THE NATURE OF A PARTNERSHIP, TO SMALL- AND MEDIUM-SIZED MANUFACTURERS BY MAKING AVAILABLE EQUIPMENT, SOFTWARE, AND PERSONNEL TO ACCELERATE THE WISE APPLICATION OF THIS NEW TECHNOLOGY. IN THE ABSENCE OF SUCH A DELIBERATE AND WIDESPREAD EFFORT TO DEMONSTRATE AND TRANSFER THE NEW MANUFACTURING TECHNOLOGY, THE TRENDS OF THE PAST EIGHT YEARS WILL CONTINUE AND WE WILL ALL SUFFER THE CONSEQUENCES.

THERE IS YET ANOTHER REASON TO PURSUE THIS PROGRAM OF TECHNOLOGY TRANSFER WITH VIGOR. IT OFFERS GREAT HOPE FOR SMALL TOWN AMERICA. THE SMALL SCALE OF EFFICIENT OPERATION OF FLEXIBLE MANUFACTURING SYSTEMS, ALONG WITH MODERN COMMUNICATIONS AND TRANSPORTATION, OFFERS THE POSSIBILITY OF CREATING JOB OPPORTUNITIES THAT CAN REVITALIZE SMALL COMMUNITIES ALL OVER OUR COUNTRY.

IT IS ALTOGETHER POSSIBLE, INDEED IT MAY WELL BE DESIRABLE, TO BRING THESE MANUFACTURING PLANTS INTO SMALL TOWNS WHERE THE QUALITY OF LIFE AND THE WORK ETHIC ARE HIGH AND THE OVERALL COST OF OPERATION IS LOW. HOWEVER, TO CAPITALIZE ON THIS OPPORTUNITY, WE MUST FIND WAYS TO DISSEMINATE THE UNDERSTANDING OF THIS AUTOMATED MANUFACTURING TECHNOLOGY AND ITS APPLICATION. THE CENTERS FOR THE TRANSFER OF MANUFACTURING TECHNOLOGY COULD BE THE CATALYST FOR THIS EFFORT.

FOR THESE REASONS, I URGE THE SUBCOMMITTEE TO FUND THESE CENTERS. $42 MILLION WILL MAKE POSSIBLE A DOZEN SUCH CENTERS STRATEGICALLY POSITIONED AROUND THE UNITED STATES. WHILE A DOZEN CENTERS MAY NOT BE SUFFICIENT TO SERVE THE MORE THAN 300,000 MANUFACTURERS IN OUR COUNTRY, WE MUST ENHANCE OUR EFFORT NOW. WE CANNOT, IN MY VIEW, ACCEPT THE RISKS THAT DELAY INVITES. THE TRENDS ARE CLEAR AND THE CONGRESS MUST NOT HESITATE WITH HALF-HEARTED MEASURES.

THIS YEAR MARKS THE 126TH ANNIVERSARY OF THE LAND GRANT MOVEMENT AND THE FAMOUS MORRILL ACT OF 1862. MORE THAN ONE CENTURY AGO, THE 37TH CONGRESS SAW THE NEED TO BRING PRACTICAL KNOWLEDGE TO THE PEOPLE OF THE UNITED STATES AND ESTABLISHED THE GREAT LAND GRANT UNIVERSITIES OF OUR NATION.

THESE PEOPLE-SERVING INSTITUTIONS HAVE BECOME THE ENVY OF THE WORLD AND, AMONG OTHER THINGS, HAVE MADE AMERICAN AGRICULTURE THE MOST PRODUCTIVE ON THIS EARTH BY PROVIDING PRACTICAL KNOWLEDGE OF THE TECHNOLOGY OF FARMING. BY TAPPING THE SCIENTIFIC UNDERSTANDING OF OUR RESEARCHERS, THE ENERGY OF INDIVIDUAL FARMERS AND THE VALUES OF RURAL AMERICA, AMERICAN AGRICULTURE HAS BEEN THE PREEMINENT AMERICAN SMALL BUSINESS FOR NEARLY A CENTURY. I BELIEVE THE CENTERS FOR THE TRANSFER OF MANUFACTURING TECHNOLOGY HAVE THE CAPACITY TO CREATE ANOTHER AMERICAN SUCCESS STORY. BY EXTENDING PRACTICAL KNOWLEDGE ABOUT MANUFACTURING IN THE SERVICE OF PEOPLE, THESE CENTERS CAN PLAY AN IMPORTANT ROLE IN REVITALIZING MANUFACTURING IN AMERICA. IN THIS WAY THE 100TH CONGRESS CAN CONTINUE THE VISION AND LEGACY OF JUSTIN MORRILL AND HIS COLLEAGUES OF A CENTURY AGO. THE OPPORTUNITY IS CLEAR. MAY YOU HAVE THE WISDOM TO PURSUE IT WITH BOLDNESS.

STATEMENT OF THE ASSOCIATION OF AMERICAN UNIVERSITIES; ASSOCIATION OF GRADUATE SCHOOLS; COUNCIL OF GRADUATE SCHOOLS; NATIONAL ASSOCIATION OF STATE UNIVERSITIES AND LAND-GRANT COLLEGES

A declining portion of the country's most talented college graduates are choosing to enroll in graduate programs and pursue careers in teaching and research. Blacks, Hispanics, and American Indians remain severely underrepresented in graduate education. As the proportion of ethnic minority groups in the total population increases, a continuing inability to recruit representative numbers of students from these groups progressively diminishes the pool of potential graduate students. Yet by the mid-1990s, student enrollments and faculty vacancies will increase simultaneously. The resultant sharp increase in demand for new faculty will have to be met with students entering graduate programs now.

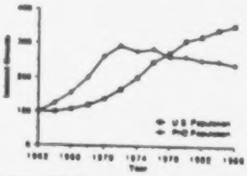
The history of federal funding for graduate education indicates the effectiveness of sound federal programs in strengthening graduate education. Following the launching of Sputnik in 1957, federal support for graduate study increased rapidly. By 1969, the number of federal fellowships, traineeships, and assistantships had reached approximately 80,000. The growth in federal support was accompanied by a comparable growth in the size of the enterprise. Just under 10,000 doctoral degrees were awarded in 1960; by 1969, over 26,000 doctoral degrees were conferred.

The period of rapid growth in federal programs was followed by a precipitous decline. Between 1970 and 1975, NDEA Title IV fellowships, NSF traineeships, NIH fellowships, and NASA traineeships were eliminated; NSF fellowships and NIH training grants were substantially reduced. Federal support continued to decline in the second half of the 1970s though the 1980s, and graduate students became increasingly dependent on loans to finance their education. From 1974 to 1984, the percentage of federal support for graduate and professional students provided in the form of loans increased from 26% to 73%.

Decline in Number of U.S. Doctorates: Between 1970 and 1986, declining federal support correlates with substantial reductions in the number of U.S. citizens receiving doctorates: the percentage of doctorate recipients in all fields who were U.S. citizens dropped from 84.5% to 72.3%; the drop in the physical sciences was from 82.2% to 62.5%; the drop in engineering was from 73.2% to 40.8%.

Figure 1 displays the changes in the number of doctorates received by U.S. citizens and permanent residents in comparison to the growth in the population pool of persons aged 25 - 34 years with at least 16 years of education, the pool from which doctoral students are drawn. The proportion of students in this country earning Ph.D.s has been steadily declining since 1972.

FIGURE 1



NOTES: Index year = 1962. Comparable U.S. population = 25- to 34-year-olds having 16 or more years of education.
SOURCES: National Research Council and U.S. Department of Commerce, Bureau of the Census.

FIGURE 2. Trends in the number of U.S. and permanent-resident Ph.D.s and in the comparable U.S. population, 1962-1986

The declining numbers of U.S. doctorate recipients has been offset by increasing numbers of foreign students with temporary visas receiving doctorates. As a consequence, the number of doctorates awarded by U.S. universities has remained relatively stable over the last decade–between 31,000 and 32,000. However, whereas more than 90% of U.S. doctorate recipients have employment commitments in the U.S., only about one-third of doctorates holding temporary visas have such commitments (92.4% vs. 35.6% in 1986).

The drop in the number of doctorate recipients who remain in this country has serious implications for our future competitiveness.

There are five programs in the Department of Education that directly address the declining enrollment of U.S. students in graduate education–four programs in Title IX, Graduate Education, and the International Studies programs of Title VI.

Title IX, Graduate Education

Two Title IX programs work in tandem to increase the enrollment of students underrepresented in graduate education–Grants to Institutions to Encourage Minority Participation in Graduate Education (Part A), and the Patricia Roberts Harris Graduate Fellowship Program (Part B). The new Part A program is a proven approach to increase minority enrollment in graduate education, providing summer research internships to talented minority *undergraduates* to interest them in and prepare them for graduate education.

The FY 1988 appropriation of $3.4 million should be sufficient to support an estimated 850 student internships. Because of the critical need to increase minority graduate enrollments, funding for this program should be increased to $5 million. This would permit the program to support up to 1250 students (still less than 2% of the roughly 80,000 college graduates per year from the targeted minority groups).

The Part B Harris Fellowships provide multiyear fellowship support for graduate and professional study to students from groups underrepresented in graduate education. As the largest federally funded fellowship program for students from groups underrepresented in postbaccalaureate programs, it is an essential instrument for increasing enrollments these students.

This year the Department expects to support approximately 530 new fellowships through this program in addition to funding continuing fellowships. In order to fund a new class next year equal to the size of this year's class, and to fund continuing fellows, program funding will have to be increased by $5.2 million to $20.5 million in FY 1989. The increased funding reflects the incorporation into new and continuing fellowships of the program improvements enacted in reauthorization.

The Jacob K. Javits Fellows Program (Part C) is the only federally funded program providing fellowship support for graduate study in the arts, humanities, and social sciences. It has encouraged some of the nation's most gifted college graduates to pursue graduate study in these disciplines.

The program needs one final year of incremental funding to bring it to a steady state as a four-year fellowship program. After FY 1989, funds needed to support new classes will be made available with funds from students whose tenure in the program has been completed.

The Department expects to award approximately 185 new fellowships this spring. In FY 1989, therefore, the program will need to be funded at $9.5 million in order to support a new competition for 185 students and to fund continuing fellowships.

Congress has shown a strong commitment to providing the incremental funding needed to carry this program forward. We ask that you continue that commitment for one more year to carry the program to its intended stable state.

The newly funded Graduate Assistance in Areas of National Need (Part D) is designed to reverse the decline in numbers of U.S. students enrolling in graduate programs in fields critical to the nation. It closely resembles the National Defense Education Act of 1958, which was highly successful in drawing new talent into our doctoral programs following the launching of Sputnik.

The FY 1988 funding of $7.7 million will support approximately 500 students. FY 1989 funding of $15.4 million will be needed to fund an equal sized new competition next year and to support the second year of this year's trainees.

Title VI, International Studies

It is difficult to imagine a set of programs more directly designed to provide the talent and knowledge base needed to sustain the nation's international competitiveness than the International Studies programs of Title VI. Title VI programs educate the scholars and experts essential for a number of critical functions, ranging from the fundamental understanding of other cultures needed by the citizens of a democratic society and their government to the advanced training in the languages and customs of other countries needed by American businesses.

Title VI should be funded at $41 million in FY 1989 in order to restore the funding cut imposed by last year's budget summit agreement and to provide $7 million for the three new programs authorized in the Higher Education Amendments of 1986–the second tier of fellowships for advanced graduate students, intensive summer language institutes, and language resource centers.

Title II, Libraries

The programs in Title II–particularly Part C, Research Libraries; Part D, Library Technology; and Part B, Library Training–provide important support for research libraries. These programs should be funded at least at a current services level.

We wish to close with some general comments about education. Education is truly a pipeline. The educational achievements of many of the students who enroll in our graduate programs and go on to pursue careers in teaching, research, and scholarship can be traced to educational opportunities made possible by elementary and secondary school programs funded by this Committee. By supporting educational opportunity and excellence at all levels, the federal government immeasurably benefits students and the nation.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

STATEMENT OF THE AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS AND CONGRESS OF NEUROLOGICAL SURGEONS

Mr. Chairman and Members of the Subcommittee,

Thank you for the opportunity to appear here today to discuss the research programs of the National Institutes of Health, and in particular those of the National Institute of Neurological, Communicative Disorders, and Stroke.

I am Merwyn Bagan, M.D., a neurosurgeon in private practice in Concord and Manchester, New Hampshire. I appear here representing the American Association of Neurological Surgeons (AANS) and the Congress of Neurological Surgeons (CNS), which have over 3,000 neurosurgeon members.

Mr. Chairman, I want to commend the Members of the Subcommittee for their decision to focus on the neurosciences by declaring 1988 to 1998 the "Decade of the Brain".

We in neurosurgery propose an ambitious agenda for this "Decade", with the public and private sectors joining to support research related to the causes, treatment, and prevention of neurological diseases. We urge that high priority for funding by the National Institutes of Health in Fiscal Year 1989 and beyond be given to activities which:

1) Implement the recommendations of the Institute of Medicine study titled "Injury in America".

Between the ages of 1 and 34, more Americans die from injuries than from all diseases combined. The treatment of injury is one of our greatest health care expenses. For these reasons, we suggest the Subcommittee give special consideration to these three injury initiatives:

-- First, provide funding for a National Spinal Cord and Head Injury Trauma Registry at the Centers for Disease Control. This Registry would allow separation of injury data for work, recreational sports, and organized sports. This data would assist in evaluating prevention programs, achieving better hospital utilization, and designing more efficient rehabilitation. The collection of this data is an important factor in reducing the number of injuries and designing advances in treatment.

-- Second, direct the National Institutes of Health to initiate specialized project grants for trauma and head injury research.

-- Third, make additional funding available for Spinal Cord and Head Injury Prevention Programs through the Department of Health and Human Services and the Department of Transportation.

2) Direct the National Institutes of Health to accelerate research support for cellular microbiology as it applies to neural implants.

In addition to implants for Parkinson's disease, other promising areas include:

-- the potential for spinal cord reconstruction,

-- the use of physiological nerve grafts to the central nervous system for resuscitation of viable neural tissue,

-- the treatment of hormonal insufficiencies,

-- the use of genetically controlled genes which may be able to reverse congenital defects and other genetic mutations.

In this regard, we urge that you make a provision for the Institute of Medicine to study the medical, ethical, and moral issues of tissue transplantation for certain neurological disorders.

3) Fund multi-disciplinary/multi-institutional research centers addressing the problem of neurological impairments, including those from premature birth.

Prematurity is the leading cause of neurodevelopmental disease. It can mark the beginning of a lifetime of physical and mental disabilities, including cerebral palsy, heart and lung disorders, blindness, hearing loss, epilepsy, and learning disabilities. The medical and economic consequences can be catastrophic.

4) Provide increased support for genetic research at the National Institutes of Health.

Additional work in cloning and characterizing abnormal genes potentially enables the identification of persons at risk for inherited diseases.

5) Implement the recommendations of the Institute of Medicine study on pain.

The recognition of etiological factors and contributing circumstances to the persistent and often permanent disabilty of patients with chronic pain is a major challenge to scientists and political leaders alike.

6) Accelerate funding for basic and clinical research in spinal disorders, including back pain.

For millions of Americans, back pain continues to be a major cause of disability and the attendant loss of time from the work place.

7) Develop a long-term, Congressionally mandated plan for the modernization of science laboratories and equipment.

This is critical if the United States is to maintain its preeminence in basic and clinical research.

Mr. Chairman and Members of the Subcommittee, I want to inform you of the "Decade of the Brain" initiatives and programs of the AANS and CNS.

We have begun a National Head and Spinal Cord Injury Prevention Program. Our pilot efforts in Missouri and Florida have convinced us that teenage behavior can be modified through carefully developed in-school and recreational site programs.

While the program has not been in operation long enough to provide reliable outcome information, we know that injury among teenagers has declined in pilot program areas.

Our Injury Prevention Program has been introduced in 18 states, and we hope to double that number by 1990. We also are collaborating with the Department of Defense, the Department of the Interior, and the Forest Service to reduce head and spinal cord injuries in their jurisdictions.

We have established a general registry of adrenal fetal transplantation at our national headquarters. Recognizing the inadequate funding available for neurological research, we established a research foundation in 1981. This is funded internally by American neurosurgery, and complements NIH research by supporting basic science and clinical investigators.

Organized neurosurgery is concerned with the continuing education of its members. By means of annual and regional meetings, official publications, and subspeciality sections including trauma, tumor, vascular, spine, and pediatric, the members are exposed continuously to the important subjects presented in this testimony.

On behalf of all neurosurgeons, I want to express our gratitude for your strong interest in biomedical research. At the same time, I offer all possible assistance to the Subcommittee so that the next decade will indeed be remembered for the great advances made in our knowledge of the central nervous system.

Thank you.

LETTER FROM PERRY B. MOLINOFF, M.D., PROFESSOR AND CHAIRMAN, UNIVERSITY OF PENNSYLVANIA

April 27, 1988

Mr. Michael Hall
Professional Staff Member
Senate Appropriations Subcommittee on Labor-HHS
Room 186, Dirksen Senate Office Building
Washington, DC 205105

Dear Mr. Hall:

With regard to current appropriation deliberations related to the National Institutes of Health and more particularly the National Institute of General Medical Sciences, I would like to offer my comments as public testimony.

By way of introduction, let me say that I am currently the A.N. Richards Professor and Chairman of the Department of Pharmacology at the University of Pennsylvania School of Medicine. I have held this position since 1981. Support from the NIH has been critical to my own career development. I received a predoctoral fellowship, awarded to Harvard Medical School, that made it possible for me to take a leave of absence from Medical School. This support and the opportunity that it entailed enabled me to conclude that a career in research was my preferred choice. After completing Medical School and an internship, I spent two years at the National Institutes of Health working in the laboratory of Julius Axelrod, who has since become a Nobel Laureate. After two years at the NIH, I received a competitive fellowship from the NIH that enabled me to spend two years carrying out research at University College in London. The bulk of my research training was thus directly supported by the NIH. My first faculty position was at the University of Colorado and the research in my laboratory there, and now at the University of Pennsylvania, has been almost exclusively funded by grants from the National Institutes of Health. I am presently the principal investigator on a program project grant entitled "Pharmacology of Receptor/Effector Systems" and a predoctoral training grant. These are both funded by NIGMS. I am also principal investigator of two individual research grants funded by NINCDS.

I have summarized above the history of my support from the NIH, both to introduce myself and to provide an example of the way in which NIH support has fostered the training and career of an individual scientist. I would now like to comment on two issues that I believe to be particularly relevant with regard to support for NIGMS. These relate to the need to provide appropriations for NIGMS to fund non-categorical research grants and the need for increased levels of stable funding to allow NIGMS to support predoctoral training of Ph.D's and of M.D./Ph.D's.

The benefit of a balanced portfolio of programs including support for centers, program projects, and individual investigator-initiated research grants is, I think, widely accepted. NIGMS, like most of the institutes at NIH, appropriately emphasizes the investigator-initiated research grant. I believe that there are some instances in which a group of investigators working in close conjunction under the auspices of a center or program project will produce considerably more than the same investigators working with the same total support but outside of a program umbrella. Nonetheless, I strongly support the decision of the institutes to emphasize individual research grants. It is my belief that science is now embarked on an effort with unprecedented opportunities for the development of knowledge that will lead to the prevention, reduction, and treatment of a large number of hitherto untreatable diseases. The application of molecular and cellular techniques to the study of basic biological processes and the relationship of the knowledge thus gained to the pathophysiology of disease have the potential to lead to important gains.

The last several years have been a time of great uncertainty within the scientific community. On the one hand, the funds available for research and the number of research grants have been increasing. These are certainly welcome developments and I believe that these increases are essential if the United States is to maintain its position of preeminence in the world with regard to health-related research. The level of funding has not, however, kept up with the increase in the number of research grants so that at the present time, funding of most research grants is being negotiated downward by between 7 and 11%. A decrease of 10% below the study section-recommended level is in most cases consistent with productively carrying out the proposed research. It is worth pointing out that study sections are made up of scientists all of whom are competing for research grants themselves. It is my perception, having served for 10 years on two different study sections, that the members of study sections are very conscientious in evaluating research budgets so that the study section-recommended levels of support are in fact appropriate for optimally carrying out a proposed program of research. If fiscal constraints should make it necessary to reduce the level of funding by more than 10%, I believe it would significantly affect the ability of investigators to carry out the research that has been proposed.

Despite the overall growth in research support over the last several years, it has been a time of enormous uncertainty, uncertainty engendered by rescissions, holdbacks, suggestions for the funding of two-year grants, and proposed limitations on the number of grants to be funded. The budgetary rescissions and other proposals of the OMB have created enormous difficulties both for the NIH and for investigators dependent on NIH support. In many cases, funding has had to be delayed. In some cases, delays are only inconvenient; in others, such as delayed funding for a competing renewal, investigators have had to lay off employees and have had to scale down or discontinue research programs. An enormous investment of both time and money is required to reinitiate a project after a delay caused by administrative decisions. It is also important to emphasize the debilitating and destructive effects of the uncertainty engendered by the various proposals that affect a stable NIH support base. There is no question in my mind that these events have contributed to the decisions of some individuals to leave science to accept positions in administration or in industry.

Finally, with regard to research funding, I would like to make some specific comments as to the importance of non-categorical funding such as is awarded by the NIGMS. Disease-related support from one of the categorical institutes is obviously appropriate once sufficient basic information has been obtained to permit informed decisions as to research strategies and approaches. In many cases, fundamental research can not be specifically associated with particular diseases. It is within this realm that the NIGMS plays a particularly critical role. I believe it to be essential to maintain a system that permits support of research whose applicability to a specific disease has not yet been established. Multiple examples of the success of this approach exist within the files of NIGMS. Such examples include molecular biological studies of the control of cell growth and of receptors for low-density lipoproteins. The role of growth factors and oncogenes in development and in carcinogenesis is, of course, now becoming clear as is the role of cholesterol and receptors for low-density lipoproteins in cardiovascular disease. Within my own area, I believe that our studies of receptors and of receptor-mediated effector mechanisms have led to very specific increases in our understanding of a variety of diseases and of the responses of disease to treatment. These diseases range from hypertension and cardiac arrhythmias on the one hand to neurodegenerative and neuropsychiatric diseases on the other. Although the eventual return from non-categorical research is difficult to define, examination of the record leads to the inescapable conclusion that this kind of research pays enormous dividends.

I would now like to turn to another major NIGMS program, that of support of predoctoral trainees. The vitality of our entire biomedical research enterprise is directly dependent on a continued supply of high-quality, well-trained young investigators. We need Ph.D.-level investigators capable of carrying out independent research in basic mechanisms of biological function and we need M.D./Ph.D.'s who can provide a bridge between basic research on the one hand and clinical application of fundamental new research discoveries on the other. As I have noted above, funds for the support of research have been increasing over the last several years. This is not true with regard to support for trainees. With the exception of increases in the budget appropriation for training linked to increases in stipend, the appropriation for support of training has been essentially unchanged during the past ten years. At the same time, tuition has been increasing by almost 10% per year. This has inevitably resulted in a dramatic decrease in the number of trainees that can be supported. A committee of the National Academy of Sciences, mandated by Congress, has provided estimates of the number of trainees required for the optimal maintenance of our biomedical research enterprise. These levels have never been met. It is particularly unfortunate that at a time when the growth of biomedical technology has created unprecedented opportunities and an unprecedented demand for trained investigators, the number of such investigators is declining. It is my belief that there should be a dramatic increase in the budget allocated for the support of predoctoral trainees.

In addition to the need to support more trainees, the stipend for each trainee should be increased. At the present time, stipends for predoctoral trainees are $6,552 per year and postdoctoral trainees have a starting stipend of $15,996 per year. It is my belief that additional funds should be appropriated to permit increasing these stipends to approximately $10,000 per year for predoctoral students and $20,000 per year for postdoctoral trainees. One additional aspect of trainee support should, I believe, be considered by your committee. The procedure followed over the recent past has been to hold stipends at a constant level for some period of time and then abruptly increase them to a new value. I would like to suggest that provision be made for a gradual, continuing increase in stipend, perhaps linked to inflation or to some other index. In addition to preventing the continual erosion of the standard of living of trainees, this kind of a policy would avoid the dislocation that occurs in the training budget each time a stipend increase is mandated.

I have commented above with regard to the debilitating effects that the uncertainties in research funding have on investigators. Uncertainties of research support and of training support have an even greater effect on students who are considering careers in research. These individuals will all have alternative career options. When they observe the uncertainties faced by their teachers, together with the stress engendered by the uncertainty of predoctoral and postdoctoral support, they very reasonably begin to wonder whether the sacrifices, uncertainties, and privation inherent in the training for a career in research are worth the effort. In this regard, I would give the very highest priority to whatever can be done to provide an atmosphere of stability to the funding of pre- and postdoctoral training programs.

I believe it is imperative to provide increased levels of stable support for pre- and postdoctoral training. I place the greatest importance on the funding of predoctoral students and combined-degree students. A variety of mechanisms exist that allow support of graduate students during the phase of their research training when they are carrying out thesis research. Since they are making definable contributions to a research program, it not unreasonable to support them with funds provided to that program. Such funds do not exist for support of students during the didactic phases of their training program, which usually takes place in the first two years after matriculation. I can cite my Department's situation as a specific example of the current situation with regard to predoctoral training. We currently have approximately 38 graduate students in our graduate program in pharmacological sciences. Almost half of these students are in the pre-thesis phase of their training program. Our training grant provides, however, for support of only 8 students. I do not believe that support of only 20% of the students in a program constitutes an adequate level of support of a predoctoral training program. Added to this is the fact that stipends must be supplemented by departmental or University funds to provide a living wage for students embarking on a career in research.

With regard to combined-degree students there are two points that I believe should be emphasized. The first is that an increased number of students should be trained so as to take advantage of the increasing opportunities and information brought on by a revolution in molecular and cellular biological approaches. In recognition of the need for such training and in response to the demand of students for advanced combined-degree training, our institution, like many others, organizes programs for students supported by MSTP funds provided by NIGMS and for students who are self-supported but still desire the opportunities of a combined-degree program. The importance of the MSTP support can be seen from consideration of the attrition rate of such students. Nearly all of the students who receive MSTP support successfully complete the program, while at least half of the combined-degree students who do not have MSTP support drop out of the program. I must emphasize that these are highly motivated and highly qualified students, but they are unable to cope with the $100,000 or more of debt they will incur during medical school, coupled with the prospect of receiving only a very limited stipend or salary with which to repay this debt.

Personally and on behalf of scientists at the University of Pennsylvania and throughout the country, I am requesting your help in obtaining increased support for research and for training. I would, of course, be pleased to provide any additional information that would be helpful to you or to the committee.

Sincerely yours,

Perry B. Molinoff, M.D.
Professor and Chairman

STATEMENT OF THE NATIONAL TREASURY EMPLOYEES UNION

I am Robert M. Tobias, National President of the National Treasury Employees Union. NTEU is the exclusive representative of over 125,000 Federal workers, including all Social Security Administration employees in HHS regional offices, and attorneys in the Office of Hearings and Appeals. I am accompanied by Patrick Smith, NTEU Director of Legislation, and Paul Suplizio, legislative consultant.

I am pleased to appear before you today to discuss the Social Security Administration's budget request for FY 1989. We are unalterably opposed to this budget and the Administration's plan to reduce SSA by 17,000 positions over six years. We view this plan, which was recommended by the Grace Commission and imposed by OMB, as a calculated assault on the machinery that serves millions of senior citizens and needy Americans.

The plan makes a mockery of the dedicated service of thousands of SSA employees who face disruption of their careers, livelihoods, and hopes for the future. We vow to carry on the fight against this ruinous policy until every one of those 17,000 positions is fully restored and SSA recovers its reputation as a place where decent, caring men and women can serve their communities.

We repeat what the staff of the Ways and Means Committee reported in 1985, that OMB's plan was developed without analysis and "driven by staffing reduction needs, rather than objective examination...there is no clear evidence that real dollar savings will result...the numbers in the plan are all very soft...the reduction figure was originally a part of OMB's budget mark to SSA, and SSA has simply been attempting to develop a plausible cover plan that could conceivably result in such a reduction in staff."

The evidence is clear that the downsizing that has occurred is not realistically related to office automation and systems modernization, because while those efforts have fallen behind schedule staff cuts have continued. The policy of the previous commissioner was: "Jobs will not be phased out until the new systems are in place and working well." For defending her agency, the commissioner was removed.

How far the Administration has gone in perpetrating its scheme is shown in Table 1. Cuts of more than 2,000 positions were imposed each year from FY 1984 through FY 1986. In FY 1987, under the present commissioner, 4,710 positions were eliminated. This year, 2,400 more are slated to go, and the last 5,400 positions are scheduled for elimination in FY 1989 and FY 1990.

SSA's final strength at the end of 1990 would be 62,945 FTE, a reduction of 17,000 positions from the FY 1984 level and 19,500 positions from the FY 1983 level. The reduction proposed for FY 1989 is 3,341 full-time equivalent positions. During FY 1988-1990, a total of 7,800 FTE's or 11 percent of SSA's authorized positions will be wiped out if OMB has its way.

As a result of these reductions, SSA is an agency in the process of unraveling, with plummeting morale, sharply deteriorating service, excessive error rates, continuing unacceptable levels of overpayments and underpayments to beneficiaries, modernization plans that are over budget and behind schedule, and mounting backlogs of vital work in field offices, program service centers, hearings and appeals offices, and disability determination services. SSA is at the breaking point, and we can expect a serious debacle to occur affecting payments to millions of beneficiaries if Congress does not act promptly to halt further cuts and restore SSA's effectiveness.

The facts bearing this out are plain enough for any objective observer to see, and will be discussed at length in our statement. We believe there is conclusive evidence that SSA "performance" and "client satisfaction" reports being fed to Congress and the American people are inaccurate and misleading representations of the true condition of SSA and ought not to be swallowed whole, but rather interpreted with the utmost care.

Last year, at NTEU's urging, the Appropriations Committees in the House and Senate attempted to call a halt to further reductions by setting an employment floor of 70,345 positions. However, after agreement had been reached on SSA funding that would achieve this goal, the bipartisan White House-Congress budget summit last December required a further reduction which resulted in a total cut of $281 million below the budget request.

This gave the Administration a pretext for further personnel cuts. SSA had a $200 million cushion from lower Federal Employee Retirement System costs ($97 million), unused data processing funds ($53 million), and its contingency reserve ($48 million). The remaining shortfall, including cost of the 2% Federal pay raise, could have been made up by reprogramming more than $200 million in unobligated data processing funds carried over from prior years. The injunction of the House and Senate conferees, in their report of last December 21st on the FY 1988 Continuing Resolution, to maintain 70,345 FTE's could have been achieved if the Administration were minded to do so. Instead, they chose to reduce SSA 2,400 FTE's this year and a further 3,341 in FY 1989.

This experience demonstrates conclusively the futility of exhorting the Administration to maintain a given personnel level, when the latter is single-mindedly committed to achieving its plan to cut 17,000 positions. Congress has the constitutional authority to appropriate funds, and has the power to specify what the funds should be spent for. Congress should therefore mandate in the appropriations bill for FY 1989 a specific floor for SSA positions, in terms of FTE's and work years.

Congress should begin by restoring the 2,400 positions slated for reduction this year, and the 3,341 positions proposed for reduction in FY 1989. Restoration of these 5,739 positions would bring SSA to the FY 1987 level of 70,784 FTE's (Table 2). If the level of 70,784 FTE's were specified in the enacting legislation, this would effectively bring to a halt any further wielding of the budgetary ax by OMB. But NTEU would go further.

Congress must immediately confront the tasks of remedying the major deficiencies in SSA's capacity to render responsive, caring, efficient service, assuring SSA's ability to maintain accurate wage and benefit records, and charting a course for service delivery to a growing number of beneficiaries in the changing environment of the next decade. Steps need to be taken to restore employee morale and pride in service, while relieving workers at all echelons of the necessity of doing their own clerical work, answering telephones, and carrying extra workload stemming from the current shortage of employees. Normal hiring rates need to be restored, so that SSA can again recruit quality personnel who will become its future office managers and supervisors. Promotions should again be opened up and career opportunities enhanced for training in the modern tools SSA employees will utilize in the office of the future.

In order to achieve these goals while focusing SSA's resources on its most pressing needs, NTEU strongly urges enactment this year of an SSA "Service Now" Initiative consisting of 5,000 FTE and $139 million in new budget authority for FY 1989.

This new initiative would:

1. Strengthen the community-based service delivery system through local offices as the principal means of serving the public;

2. Improve processing times, payments accuracy, and quality of earnings and benefits information available to the public;

3. Reduce delays in reconciling earnings records and recomputing benefit payments so that beneficiaries are not underpaid;

4. Reverse the "hollowing out" of the agency that has occurred from allowing backlogs to build in lower priority, but vital, work areas such as post-entitlement actions;

5. Dramatically reduce processing times for cases in Appeals by authorizing OHA staff attorneys to adjudicate medicare and SSI reconsideration cases through a new personal conference procedure similar to that used to resolve overpayments; and

7. Improve morale and retention of career employees while enhancing working conditions, promotion and training opportunities, and better management of technological change.

In the sections that follow, we will present detailed justification for each of the above proposals. But first let's recapitulate NTEU's budget proposal for SSA for FY 1989. Congress needs to restore 5,739 positions cut by the Administration in FY 1988 and FY 1989, at a cost of $159.5 million. This will check further cuts, but it will not correct the hollowing out of the agency stemming from the 8,000 positions eliminated from FY 1984 to FY 1987.

Consequently, it is imperative that Congress take action to repair the damage caused by past reductions and restore SSA to peak effectiveness. NTEU's proposed "Service Now" Initiative, totaling 5,000 positions and $139 million, is tailored to start with the major problems SSA confronts today and apply the resources needed to resolve those problems. Including this initiative, NTEU's total recommended additions for FY 1989 come to 10,739 average positions costing $298.5 million. NTEU's recommended appropriation for SSA for FY 1989 is $4,074,205,000 and 75,784 average positions (Table 2). The staff additions to each SSA component, resulting from our recommendations, are presented in Table 3.

We should recall that it is the workers and employers of the nation, through their FICA taxes, who pay for every cent that is expended to administer the Social Security system. In hearings over the years, beneficiaries have constantly expressed the theme that they are willing to pay the cost for prompt, efficient service bringing relief from stress and worry about their paychecks. The cost of service today is only 1 cent out of every dollar of benefit payments. In this light, the extra resources we recommend are not large in relationship to the needs of 37 million beneficiaries. Surely, we can afford to give SSA the resources it needs to do its job, rather than allow the agency to be debilitated by the arbitrary employment goals of a particular Administration.

In order to insulate SSA from the caprice of any future administration, NTEU strongly supports establishment of SSA as an independent agency. We believe this vital agency should be renamed the Social Security Service to emphasize its mission, and should have independent authority over both mission accomplishment and management of its personnel. Several bills aimed at establishing an independent SSA have been introduced in Congress. We do not believe any of these bills go far enough to uphold and protect the rights of SSA's beneficiaries and employees, and we are prepared to work with Congress in writing legislation that will meet the needs of the American people.

Strengthen The Community-Based Service Delivery System

The direction the Administration would take SSA is plain enough to see. Its blueprint is the Grace Commission report. Grace recommended consolidating local offices from 1,300 to 500, and reducing personnel accordingly. This was rightly perceived in Congress as an outright assault on the community-based service delivery system that is essential to rendering responsive service to the American people. When the Administration's plan to consolidate local offices was discovered in 1985, the public outcry caused it to be shelved.

To remove any doubt of the Administration's intentions, NTEU obtained from HHS a summary of the status of Grace Commission recommendations. Grace recommended: "SSA -- Create larger offices as backbone of system. Reduce number of offices to 500, and reduce employee populations accordingly." HHS responded: "Partially implemented....41 district or branch offices closed, converted, or downgraded and 605 contact stations closed since 1981." It is difficult to conceive a more callous document. The needs of ordinary citizens who depend upon Social Security offices in their communities aren't even mentioned.

There is little doubt that the Administration's plan to reduce employment by 17,000 is simply another way to achieve its discredited effort to dismantle the community-based service delivery system. Were the Administration to succeed in making these position reductions, effectively eliminating at least 20,000 jobs or roughly a quarter of SSA's strength, is there any doubt that local office consolidation wouldn't follow?

Part and parcel of this design is the effort to make SSA an agency that provides the bulk of its service by mail and telephone. In this budget are millions of dollars for a major procurement of new telephone equipment and service. We have no objection to telephone service and recognize that teleservice plays a vital role in service delivery. We welcome and support efforts to expand and upgrade such service. But we draw the line if it is contemplated, as we believe it is, to gradually withdraw from face-to-face contact with our customers and conduct the bulk of our business by mail and telephone.

We believe such a policy would not only be more costly because of the difficulty in calling or writing to obtain facts and track down documents, but would also result in less responsive service. More importantly, we believe face-to-face contact with people in the community is essential to the delivery of caring service. SSA employees are called upon to help fellow citizens obtain benefits to which they are entitled under laws often too complex for many to understand. We are concerned that a mostly telephone/mail service delivery system would cause the relationship with real people to become more impersonal and more adversarial. We feel the community-based service delivery system is not only more responsive and less costly in the long run, but more attuned to the caring, dignified treatment beneficiaries deserve.

Vital changes are underway in society that make strengthening service delivery through field offices more imperative. According to data from SSA's strategic plan, the number of Americans over 65 will increase by 5 million by the year 2000; the number of potential disability cases will rise as our population matures; and new retirees will have a longer life expectancy. The baby boom generation, although not ready to retire, will create a much larger volume of wage reports to be accurately posted. The American household will continue to be highly diversified, with single-parent families, childless couples, and diverse groups of people living alone -- the young, divorced, unmarried, and elderly.

These conditions will make routine tasks, such as establishing entitlements eligibility, much more difficult. At the same time, the social security laws have grown more complex. Recent years have seen the addition of major new benefit categories with different eligibility requirements, and increased complexities in benefit computations.

SSA will face formidable challenges in coping with this changing environment. Its backbone must be a community based service delivery system that is in place and operating at peak effectiveness before the 1990's are upon us. We pledge to work with Congress to this end, and our "Service Now" Initiative will go a long way toward accomplishing it.

As a first and priority step, we must rebuild the capabilities of our local offices. Tables 4 and 5, taken from GAO reports on staff reductions, show the extent of cuts in field offices. In FY 1987 alone, 3,000 jobs were eliminated, bringing the total loss between FY 1984 and FY 1987 to 4,400 jobs. Our "Service Now" Initiative would restore 2,500 of these positions in FY 1989 (Table 3), with the remainder to be restored in FY 1990.

Improve Quality Of Service

GAO's most recent quality of service report (HRD 88-97) was submitted last month. It shows deterioration during the past year in 8 of 22 indicators of SSA performance, including RSI and SSI process accuracy, increased processing times for hearings and SSI aged claims, and increased backlogs of SSI aged cases, RSI claims and RSI and SSI overpayments, and of cases in Hearings and Appeals.

SSA continues to provide Congress with some fanciful statistics concerning average wait times in local offices. A gauge of the reliability of those statistics may be found in GAO's report last Fall (HRD 87-139BR) which observed:

> "Our visits to 13 offices indicate that SSA's field offices still know when wait time is being measured and some still use practices that can favorably influence the results. Further...it does not measure all of the time clients wait before being served....SSA's wait time as measured for the quarter ended September 1986 indicated that 8 percent of clients waited more than 30 minutes for service. Our survey in September 1986 of persons who had recent contact with SSA showed that 30 percent said they waited 30 minutes or more."

Recent testimony by the American Association of Retired Persons confirms this view:

> "Those visiting an SSA local office report extended waits. Even after they get to a claims representative, they may encounter an overworked and frustrated employee, unable to spend adequate time with a beneficiary because of a quantitative performance standard."

When GAO questioned employees in the 13 offices it visited, about half said service was not as good as two years ago and that complaints from the public had increased. Complaints about phone accessibility and longer waiting times were cited most frequently.

GAO surveyed SSA's telephone accessibility last year, finding that 33 percent of all calls experienced "difficult access". Calls on hold longer than two minutes, disconnected, terminated after 10 rings, or getting busy signals were characterized as "difficult access" (HRD 87-138).

At the request of Congress, GAO has periodically performed client satisfaction surveys (HRD 86-8 and HRD 87-103BR). From a questionnaire sent to clients who have had recent contact with SSA, GAO obtains a rating of overall satisfaction with mail, phone and office contacts. In the most recent survey for November, 1986 about 81 percent of clients rated SSA service as "good" to "very good". Only about 6 percent of respondents considered SSA service "poor" to "very poor".

We believe these results do not reveal the actual condition of SSA's service delivery system, and there are explanations for these results that are quite independent of the deterioration that is taking place in service delivery. First, SSA makes monthly payments to about 42 million persons, so even a 6 percent unfavorable rating translates into 2.5 million dissatisfied clients. Second, persons who are dependent on their social security checks may be thankful for the result and not inclined to criticize the process by which they were served.

We do not believe client satisfaction surveys, by themselves, are a good indicator of SSA's ability to deliver accurate, efficient service. Many are not aware they are being overpaid or underpaid. SSA employees are trained to render courteous, dignified service and we are confident they make every effort to do so. But that does not mean they are being given the time and tools they need to get the job done right.

Taking a simple post-entitlement action as an example, in only 10 percent of the cases does a change of address notice received from a beneficiary take effect prior to the next paycheck.

Error Rates in RSI Program Are Rising

GAO noted a significant decline in accuracy of processing initial claims in the Retirement and Survivors Insurance (RSI) program. SSA attributed the decline in accuracy to implementation of DOFA -- District Office Final Authorization -- whereby decisions are made in field offices for cases formerly processed in program service centers. In our testimony last year, NTEU warned that this would not only disrupt career ladders for Claims Authorizers in PSC's, but would lead to a drop in accuracy. Our expectations have been confirmed. GAO reported that "the drop in accuracy from fiscal year 1986 to 1987 represents a 14-percent increase in the incidence of cases with dollar errors." In addition to dollar errors, "other errors" in processing RSI claims increased by 37 percent. The drop in accuracy caused the over or under payment of $1.5 billion resulting from DOFA, which was supposed to save money by reducing staff.

The RSI program is the largest administered by SSA. In FY 1988, an estimated $192 billion in benefits will be paid to 34.6 million beneficiaries. Errors in processing RSI cases are thus highly significant. GAO noted in its report that --

- SSA reports only payments accuracy to Congress, which does not make apparent the 14 percent increase in cases with errors;
- In measuring payments accuracy, SSA includes everyone in current pay status, many of whose cases were adjudicated years ago; it does not measure accuracy of payments currently adjudicated.
- Error rates have been increasing since FY 1985 (Table 6).

In a report published last October, Payment Accuracy Rates Are Overstated (HRD 88-10), GAO found that --

- Not all errors are included when SSA calculates accuracy rates because of how SSA interprets errors. "GAO believes actual error rates are about twice what SSA calculates.";
- Counting all detected errors for 1986, the case accuracy rate was about 87.3 percent, rather than SSA's 94.1 percent. This means about 4.2 million persons were overpaid or underpaid $1.1 billion. During 1981-1986, an average of 4 million cases

per month were affected by errors. Cases remained in error an average of 5 years;

- SSA's reported accuracy rate did not include any underpayments or certain overpayments, "because SSA did not believe these should be reported as errors";
- Almost 60 percent of errors are underpayments, averaging $591 per case in 1984. GAO found the average underpayment to be 4.4 percent, which we calculate to be $34.32 per month for the average recipient in 1984. For a typical elderly couple age 65 or over, the underpayment represents about 6 percent of total yearly expenditures in real purchasing power, according to GAO;
- About 40 percent of errors are overpayments, averaging $1,069 per case in 1984;
- About three-quarters of underpayment problems were the fault of SSA, often the result of incorrect computation. More than half the overpayment problems were the result of beneficiary error. "Because of the nature of the errors, most (89%) would not have been likely to be detected by routine SSA processes" (emphasis supplied), GAO noted.

A key point about these GAO reports is that error rates, measuring both payments accuracy and processing, began to rise in 1986 and 1987 after having fallen the previous five years. This is a clear signal of the overall deterioration in SSA's operations that we have warned of, and requires prompt attention by Congress.

An important means of reducing underpayments is to ensure prompt recomputation of benefits for those who continue to receive wages or self-employment income. This is the task of SSA's Automatic Earnings Reappraisal Operation (AERO) under which benefits are to be recomputed within 21 months for eligible beneficiaries. Under both GAO and SSA definitions, cases requiring recomputation of benefits are not considered in error until 21 months have elapsed. We believe SSA should make every effort to reduce this period to at least an annual computation. GAO found (HRD 84-71) that in 1980 SSA underpaid 2.5 million beneficiaries at least $1.98 billion, and it took an average of 34 months until the underpayments were rectified. Even so, GAO's more recent work (HRD 88-10) shows that even if AERO were working perfectly, only about 11 percent of underpayment errors could be fixed by recomputation of benefits. The remaining 89 percent of errors require SSA to institute new procedures to detect and correct cases of underpayment.

Assure Prompt And Accurate Crediting of Earnings

Recently, SSA reported considerable progress in clearing up the backlog of discrepancies on W-2's submitted by employers that do not reconcile with quarterly tax reports submitted to IRS. GAO reported last year (HRD 87-52) that SSA had recorded $58.5 billion less in earnings than IRS for 1978-1984, and that up to 9.7 million individuals could have uncredited earnings in social security accounts because of differences between the two agencies. A typical retiree whose wage record was not up to date would lose an average of $16.81 a month for 31 months. Moreover, discrepant wage reports were piling up at more than 500,000 a year, and employers' records needed to reconcile discrepancies are required by law to be retained for only four years.

Amidst the furor that resulted, SSA says it reduced the 1978-1984 backlog from 3.5 to 1 million discrepant wage records by the end of December 1987, and will clear up the remaining backlog by March 1989, at a cost of 700 workyears. However, the picture is not really so rosy. Of the 2.5 million discrepancies worked on to date, in 1,052,000 cases employers had not responded to SSA's inquiries. Thus, SSA will need to apply staff resources to this problem for some time.

To prevent future backlogs, an interagency agreement was concluded between SSA and IRS which states essentially that (1) SSA will resolve the backlog of wage discrepancies for tax year 1978 through tax year 1986; (2) Beginning in tax year 1987, SSA will make the initial contact with employers to resolve issues; any unresolved differences will be turned over to IRS to handle; and (3) IRS will begin assessing penalties on non-responding employers now, and on late filing employers beginning in tax year 1988.

SSA recommends that workers check their wage records every three years in order to verify the accuracy of their accounts. However, we believe SSA can and should do more. As the education level of the American people rises, greater interest is emerging in financial planning. Particularly for younger workers who are uncertain whether Social Security will benefit them, a regular report of the status of their wage account and projected benefits under assumptions provided by the worker should become a regular part of SSA's service. We urge Congress to make this service a high priority and provide the resources needed to enable SSA to provide it.

Reverse the "Hollowing Out of SSA's Operations

In 1986, GAO visited fifteen field offices that had experienced staff reductions of 25 percent or more since 1984 (HRD 87-66). Of the 50 claims and service representatives contacted, 43 said staff was being overworked and backlogs were getting larger because current staffing was inadequate. Typical comments were:

> "The clericals -- claims development clerks are GS-4's who are so short staffed, they are being worked to death....Staffing shortages are so acute that Claims Representatives have to take turns processing social security card applications....Forty percent of my time

> is spent doing work formerly done by clericals. We work like hell and can't keep up the pace."

GAO noted:

> "Positions most frequently mentioned as understaffed were clericals, claims representatives, and service representatives. A manager stated that clericals are important in keeping the voluminous claims paperwork flowing. He said the position experiences frequent turnover and it is difficult to find replacements. Several personnel commented that clerical shortages require higher graded personnel to perform the clerical duties, which represents an inefficient use of resources....There was general agreement that additional future reductions in the offices would adversely affect service."

GAO also surveyed mid-level managers throughout SSA. Addressing the staff levels existing in June, 1986 about two-thirds of managers surveyed said their units had less staff than they needed. Managers believed their understaffing was detrimental to the service they provided (e.g. poor phone service, long wait times, increased backlogs). In their opinion, additional staff would enable adequate service to be provided in these areas. Instead, field offices lost an additional 3,000 jobs in 1987 (Table 7).

The two factors which mid-level managers cited as greatly affecting declining performance were changes in staff levels and in staff morale. About 66 percent of the managers had lost staff in 1985, and 71 percent believed the staff loss had a negative effect on their unit's operation. The most frequently mentioned effects were decreased quality of work and less work processed, added work for remaining employees, increased client waiting time for service, loss of best or key employees, lower morale and more stress and frustration, and shortages of support or clerical staff. Typical managers' comments were:

> "Heavy loss of trained personnel has affected the quantity of work, the quality of work and significant negative effect on morale/frustration levels....We are reaching the point where instead of doing more with less, we are doing less with less....Today we are doing much of our work using temporaries, college work-study students, summer aides, stay-in-schoolers. The constant training of these employees due to turnover impacts heavily on management time. We are holding the line with their help. If they leave -- problems.... Clerical losses caused other positions to absorb clerical tasks. Everything suffers....The ratio of marginal performers to high quality performers increased."

The trend in field office staff composition is shown in Tables 7 and 8. Clearly evident are the impacts of budget cuts and introduction of the claims modernziiation program (CMP). There was an 11 percent loss of clerical staff in 1987 alone. The number of Claims Representative Trainees has fallen sharply, even though high-calibre trainees become the professional staff of the future. When trainees move into Claims Representative positions, they should be replaced by new recruits, but this is not happening. Particularly troublesome is the increase in the number of Generalist Claims Representatives. SSA is shifting away from program specialization in handling RSI/DI and SSI claims, "to increase the offices' flexibility in dealing with workload fluctuations and reductions in staffing" (HRD 87-139BR). In reality, what this means is diminished expertise and more errors. The complexity of our social security laws requries more, not less, specialization and training.

GAO surveyed SSA employees about the effects of staff reductions, and found that 56 percent believed the losses they had experienced had a negative effect on the ability of their units to produce quality work. The most frequently mentioned effects were larger workloads to process for remaining staff, lower morale and more stress, apathy, frustration, backlogs and untimely processing of workloads, less accuracy, and tasks inappropriate to their grade level.

Employees made the following comments, paraphrased by GAO:

- As a result of staff cuts, remaining employees must work in a crisis mode much of the time. Individual leave is at a premium. The resulting burnout causes more sick leave usage, with a corresponding burden on the employees present and doing the work. The computer system has had periodic problems that grossly affect processing our claims; together, the two (loss of employees/ computer inefficiency) leave remaining employees with low morale, high frustration, and low job satisfaction. In the last 6 months, five GS-10 employees left for other endeavors as the problems and lack of management appreciation became too great to deal with any longer.

- We have lost so many people, we are barely able to keep up with current workloads and the backlogs just sit. Everybody has taken on extra duties so that you are doing the work of 3 or 4 people all the time. It is so frustrating and depressing sometimes I feel like giving up.

- Our quality is still good, but the effort needed to produce the work is greatly increased. Some employees are handling the extra stress without difficulty, but others will need more attention from their supervisor. An occasional pat on the back goes a long way.

- I believe the work is correct more often and we are doing a larger volume of work than 3 years ago. However, we feel that we are in a "crisis mode more often." We have to do a larger quantity of work per person and we are not given additional time or encouragement.

SSA's management of staff reductions has been particularly abysmal in the Program Service Centers, which have borne significant staff cuts (Tables 9 and 10) as well as upheaval in the critical Claims Authorizer positions caused by shifting final claims authorization from PSC's to district offices. In a misguided effort to save staff, the most complex and error-prone cases that were formerly handled by CA's have been thrust upon District Offices which lack the experienced and trained people to handle this additional workload. NTEU said last year that this policy -- called DOFA for District Office Final Authorization -- would only lead to higher error rates and overpayments, and this has been borne out by GAO.

The attendant organizational upheaval in the PSC's caused by the loss of the key Claims Authorizer positions has disrupted career progression and could lead to extensive reclassification of these personnel, as well as relocation of CA's to field offices. The uncertainty created in PSC's as a result of such staff changes is both debilitating to morale and the cause of departure of some of SSA's most competent and experienced staff.

SSA entered the period of staff reductions with critical service delivery problems. These problems will become more acute as a result of the budget cuts planned for this year. Among the more serious problems that require additional staff resources, not less, are:

- Post-entitlement actions, particularly updating earnings records and adjusting benefits for beneficiaries who work, are still largely handled manually and the workload is neither well-controlled nor timely posted. Overpayments result from errors and slow updating, and these overpayments are costing the government $2 billion a year -- only 65 percent of which is retrieved through collection action.

- SSA employees experience a high degree of frustration in delivering adequate service to Medicare beneficiaries who seek assistance. Problems involve establishing Medicare eligibility, issuing a Medicare card, and paying Medicare claims. Notices and other public information tell beneficiaries to contact SSA if there are any questions, and SSA provides this service under agreement with HCFA (Health Care Financing Administration). SSA employees frequently cannot answer basic questions, such as, "Was my Medicare bill paid?" without contacting HCFA or a Medicare contractor for information, and problems continually arise. According to GAO, "these situations are upsetting to beneficiaries, are frustrating to employees because they cannot help the beneficiary and have difficulty getting quick resolution, and reflect poorly on them because they appear incompetent to the beneficiaries." At bottom are difficulties in linking HCFA and SSA data systems, but competent staff are also required to resolve such problems.

- District Office Workload Reports summarize 78 different categories of SSA field office workloads reported weekly to central office. The data for 10 of the 78 categories are systems generated, the remainder are manual counts from tally sheets maintained by field office employees. When GAO asked employees in 13 offices whether the workload reports were accurate, only 32 percent said they were generally accurate. Obviously, the accuracy of these reports affect SSA resource allocations, and to the extent pending workloads are understated additional workyears are required.

- In only two of thirteen offices GAO visited did employees feel they were doing a good job processing lower priority, non-claims workloads in timely fashion. Mentioned most frequently as not being processed timely were requests from SSA components for assistance; overpayment collections; certain continuing disability reviews; SSI change of address, death, and income reports; earnings enforcement actions; representative payee actions; and earnings discrepancies. The two most frequently reported reasons given for offices doing a fair or poor job in processing nonclaims workloads were (1) insufficient staff and (2) other work has higher priority. Over half the service representatives interviewed told GAO that postentitlement work is suffering most because of insufficient staff. "At most offices, service representatives are required to spend time working the reception area. Several service representatives said that the pressure to process the face-to-face work volume leaves little time to return follow-up telephone calls to the public or to process incoming mail", GAO reported.

Development of postentitlement software has now been delayed indefinitely, although SSA has long maintained that the postentitlement area is the most error-prone. In February, 1986 SSA identified 20 continuing problems in the postentitlement process, including:

- inability to quickly process beneficiary name and/or address corrections and changes;

- excessive delays in reissuing missing or stolen checks;

- delays in changing the records of a deceased beneficiary, which result in incorrect payments to survivors;

- duplicate posting of beneficiary remittances in overpayment cases (this problem results in a significant manual work load); and

- inability of the system to automatically process requests by beneficiaries to recompute payment amounts (such requests must be processed manually).

By allowing our "Service Now" Initiative, Congress should take the lead in pressing SSA to give a high priority to upgrading its postentitlement processing systems.

Improve Morale and Retention of Career Employees

In August, 1987 SSA distributed a 39-item opinion poll to its 9,000 supervisors and managers to assist in "gauging the morale and communications needs of SSA's managerial workforce." The response rate to this mailout was 55 percent. While only the executive summary has been released, the responses are quite striking. Dissatisfaction with SSA's downsizing process was expressed by 67 percent of the respondents, with operations managers (70.8 percent) more dissatisfied than staff supervisors (58.2 percent). About one-third of respondents said they rarely leave the office with a sense of accomplishment, and less than one-fourth recommended SSA as a good place to work. A majority of managers (76.9 percent) said SSA was not a better place to work than it was a year ago. Only one in ten believed that things would improve.

When asked to characterize the morale of employees reporting directly to them, the responses suggest that those with poor morale outnumber those with high morale by almost a 2 to 1 margin. Concerning their own morale, managers were about evenly split -- 40.4 percent said their morale was high and 42.3 percent said it was poor; the other 17.3 were "unsure" (HRD 88-97).

These results confirm a report issued by GAO last year (HRD 87-66). GAO's survey found that 53 percent of employees characterized the morale of their units as generally to very low, compared to 19 percent who said it was generally to very high. Employees who cited low morale give the following reasons:

	Percentage of Employees Citing This Factor
Poor promotion potential	63
Too much emphasis on measures such as timeliness, productivity, etc.	56
Not enough emphasis on employee development	54
Uneven workload distribution	47
Poor supervision in unit	35
Expectation of a reduction-in-force	35
Poor management in unit	32
Lack of stable leadership in SSA	30
Uncertainty as to future of job	26
Necessary training not available	22
Uncertainty as to future of unit	20
Increasing technological change	17
Other reasons than those listed	32

The GAO survey confirms what NTEU has repeatedly emphasized, that the most important factors responsible for low morale are lack of promotion opportunities, insufficient emphasis on professional development, excessive workloads, and production pressure created by managers who are held accountable in their performance rating for attaining statistical goals.

Aside from the issue of low morale, employees surveyed indicated general dissatisfaction with management concern for employees (43 percent), the pay they receive (38 percent), and their career progression (37 percent). These factors contribute to an exodus of some of SSA's best talent (HRD 87-39). The Commissioner testified recently that the attrition rate for permanent employees had risen to 9 percent, compared to a historical average of 5-6 percent.

GAO found that 63 percent of the claims and service representatives said that management did not demonstrate much concern for them when major organizational or operational changes were made. About 32 percent of mid-level managers said that management did not give much attention to human factors, such as fear of change and the concerns of affected staff, before making operational changes. GAO attributed these perceptions to the fact that employee input was not sought on decisions afffecting them, that management has failed to demonstrate by action that it is attempting to address employee concerns about diminished opportunities for advancement, and that management is too concerned with production statistics.

Just as insufficient pay and career opportunities are causing some of its best people to leave SSA, inadequate training and professional development are a barrier to the type of motivated, skilled employee that SSA needs to retain in order to provide a solid cadre of professionals in the 21st century. GAO found that, of the nonmanagerial employees, more than 50 percent believe that few opportunities exist for them to receive job-related training, 57 percent believe they receive less training than needed to develop their career potential, 54 percent attributed low morale to not enough emphasis on employee development, and when asked what single management or operational change each employee would make in priority order, employees selected "enhance promotion opportunities" first and "improve training and development" second.

Of the mid-level managers, 64 percent believe SSA's training program for administrative or clerical support staff is organized and comprehensive to little or no extent, 44 percent said SSA's training courses do not meet employees' development needs, 61 percent believe that training funds are available to their unit to little or no extent, and 59 percent believe that internal training and development programs have not generally improved the performance of administrative or clerical/ support staff. In SSA's own management survey, a sizeable proportion (43.4 percent) expressed dissatisfaction with current opportunities for training. This fact is striking in view of SSA's commitment to new technology at the workplace.

SSA's training budget in recent years is show below:

Fiscal Year	Training Costs
1985 actual	$143 million
1986 actual	$131 million
1987 actual	$101 million
1988 estimate	$141 million
1989 estimate	$125 million

In FY 1987, the year in which the Claims Modernization Program was introduced, training was cut back 30 percent from the FY 1985 level. While these funds are to be restored this year, they will be reduced again in 1989, whereas undoubtedly training needs will rise because CMP will be fully installed in all 1,300 local offices by December 31st of this year. NTEU's "Service Now" Initiative includes sufficient funds for a training budget of $170 million in FY 1989.

GAO concluded:

> "SSA's potential leadership problem appears to extend all the way to its entry-level positions. According to agency officials, SSA relies heavily on internal promotions from its clerical or entry-level professional position ranks up through journeyman positions and beyond. These officials expressed a concern about increasing difficulties in attracting or retaining high-quality clerical and entry-level staff....Many mid-level managers are concerned about the quality of the entry level recruits who, through SSA's "promote from within" policy, are forming the pool of future supervisors and managers. Some managers believe that many employees with the greatest potential for advancement are leaving SSA due to uncertainty of their jobs. (Emphasis supplied).

We concur with this judgement, which underscores the necessity for adopting NTEU's "Service Now" Initiative and recommended budget plan without delay.

Staff Reductions and SSA Modernization

Instead of planning to let go more than 20 percent of its dedicated work force, SSA should be focussing attention on the steps required to modernize operations for the 21st century. The struggle over staff reductions has turned the agency's leadership away from its principal challenge, which is to manage the introduction of the latest technology so that SSA can remain an efficient service.

When it announced the Systems Modernization Plan in 1981, the Reagan Administration declared that SSA's computer systems were in a state of crisis and a major effort would be required to upgrade them. Six years and $600 million later, the computer system is still in crisis, systems modernization is behind schedule, and the entire program has been refocussed to concentrate mainly on software and telecommunications.

Despite the positive attitude of employees toward modernization, the Claims Modernization Project has not turned out well. The project requires considerable staff training as well as a learning curve that includes some short-term productivity losses. It is being implemented in field offices at the same time that staff are being cut. The end result has been to increase work pressures on employees, who are required to learn new systems while maintaining standards on existing workloads. CMP has thus had a generally negative effect on employees, because there is not enough time for staff to complete routine workloads and be trained to use the new system. The pending claims workload has grown substantially in some locations because, during the initial learning phase, it takes longer to process claims through a new system. Management's need to show progress through production statistics, which is most intense in the claims area, has increased stress and pressure on employees to work overtime and on weekends. An inordinate level of computer down time and the need to reprocess cases dropped by computer malfunctions have increased the frustration of the work force.

As of March of this year, CMP was established in 600 field offices, and SSA planned to complete installation of 22,000 terminals in all 1,300 offices by year-end. CMP has also undergone a major change in project design by limiting it to processing initial claims, and deferring development of a system to process post-entitlement actions. Since post-entitlement software processes 94 percent of beneficiary-related computer transactions, and CMP software will process 2.2 percent of these transactions, the scale of the reduction is obvious.

In 1982, SSA estimated that it would require $478 million to modernize its systems, which would take 5 years. In 1985, SSA estimated that total modernization costs would be $990 million and would extend through FY 1990. In 1987, SSA estimated costs through FY 1988 alone of $642 million, and it is requesting another $220 million for FY 1989. Clearly the program will extend well into the 1990's.

SSA's most significant challenge is to implement the technology needed for an efficient and effective service, capable of providing timely, accurate assistance to beneficiaries and a favorable climate at the workplace. Such a plan would in the long run save the American taxpayer billions of dollars, far more than the sums involved in the wholesale disruption of the agency in pursuit of staff reductions.

Will SSA's employees be affected by modernization? Of course they will. But it is the intention of NTEU to see to it that promotion opportunities are kept open, that individuals are trained for new job opportunities, that management will be engaged by contract to reassign employees to new positions only after the requisite training and with full respect for employees' rights safeguarded by our agreement, that both basic and incentive pay are provided in appropriate cases, and that professional development to ensure career progression are given high priority. NTEU is at the cutting edge in the management of change in the Federal service. We do not fear technology. We welcome its use in the workplace as long as it contributes to efficiency and lends dignity to the labor of each worker.

Reduce Office of Hearings and Appeals Processing Times

Steadily worsening processing times for cases in the Office of Hearings and Appeals have been a matter of continuing concern. From 1986 to 1987, processing times increased from 178 to 211 days -- about 7 months to resolve the average case. At the same time, the backlog of cases pending decision increased by more than 30,000 -- from 117,793 to 148,398.

SSA attributes this increase to larger case receipts, but staff reductions have also played a part. OHA is now receiving requests for hearings at the rate of 24,000 per month, compared to 16,000 in FY 1986. Table 12 shows that full-time permanent employees in hearings offices decreased by 120 from September, 1986 to June, 1987. All told, 38 administrative law judges, 30 decision writers, and 38 hearings assistants were lost.

SSA now plans to reverse course and hire around 80 new judges this year. At the end of FY 1988, SSA plans to have about 700 judges on duty -- approximately the same number as at the end of FY 1986. SSA also says it expects to increase productivity by reassigning staff, transferring workloads, and automating case files. We believe this is wishful thinking, and that backlogs will continue to mount unless more serious steps are taken.

NTEU believes that the proper course is a modest increase in staff coupled with realignment of staff responsibilities within OHA. Our proposal is not radical, for it is already in use elsewhere within SSA.

The first step would be to restore 185 positions slated to be cut in FY 1988 and FY 1989. Since the Administration has decided to hire additional ALJ's this year, it presumably sees the wisdom of ceasing further cuts in professional staff. NTEU's "Service Now" Initiative would also add an additional 110 FTE's for more staff attorneys to assist in coping with the growing workload (Table 3). Congress should firmly insist on adequate staff.

NTEU proposes that staff attorneys within OHA be assigned responsibility to adjudicate certain of the simpler cases that come before OHA, namely appeals concerning Medicare claims and SSI redeterminations. In many Medicare appeals, for example, the issue is simply whether a particular charge is allowable. Such cases lack the complexity of, say, a disability appeal. Having OHA attorneys dispose of such cases would be a far more efficient use of staff than establishing an appellate branch within HCFA, as is now being contemplated. A decision by a staff attorney could be appealed to an ALJ.

Under this concept, an OHA staff attorney would hold a personal conference with the appellant similar to personal conferences held by SSA with persons who contest overpayment decisions. The personal conference should be seen as a means of perfecting the evidence and adjudicating a case without going to the ALJ level, thereby screening out a large number of the simpler cases and reducing the workload of ALJ's. The OHA staff attorney would be responsible for gathering the relevant evidence, to include such preliminaries as ordering consultant physician examinations.

Processing times would be reduced not only because many more cases would be decided, but also because, under the present system, when a case finally gets before an ALJ, it is frequently only then determined that some action like ordering a physician's examination is required. This presents additional delay. NTEU's proposal would also achieve more face-to-face interviews earlier in the appellate process, which is beneficial because such interviews frequently lead to resolving the case.

In sum, NTEU's proposal would assign adjudicatory responsibilities in simpler cases to OHA staff attorneys. Such officers would be charged with collecting the necessary evidence, holding a personal conference, and making a determination subject to appeal to an ALJ. We have no doubt that the corps of staff attorneys within OHA have the professional competence to assume such responsibilities.

Our proposal could save millions of dollars by more efficient staff utilization within OHA, and avoiding the necessity of setting up a separate hearings and appeals office within the Health Care Financing Administration. HCFA has requested $8 million and 154 FTE to establish such a unit in FY 1989, and these resources could be saved by adopting NTEU's proposal. In the interest of sound management, we urge that our proposal be given a fair trial.

Mr. Chairman, this concludes my statement. I will be happy to answer any questions.

Table 1

SOCIAL SECURITY ADMINISTRATION—LIMITATION ON ADMINISTRATIVE EXPENSES

Fiscal year	Full-time equivalents		
	FTE's	Change from prior year	Cumulative change
1983 actual	82,483		
1984 actual	79,951	−2,532	−2,532
1985 actual	77,741	−2,210	−4,742
1986 actual	75,494	−2,247	−6,989
1987 actual	70,784	−4,710	−11,699
1988 estimate	68,386	−2,398	−14,097
1989 estimate	65,045	−3,341	−17,438

Fiscal year	Total work-years		
	Work-years	Change from prior year	Cumulative change
1983 actual	88,254		
1984 actual	86,185	−2,069	−2,069
1985 actual	82,131	−4,054	−6,123
1986 actual	78,746	−3,385	−9,508
1987 actual	72,721	−6,025	−15,533
1988 estimate	70,070	−2,651	−18,184
1989 estimate	66,305	−3,765	−21,949

Note that the long-term FTE plan projected a reduction of 17,006 FTE's over the 6-year period from the end of fiscal years 1984 to 1990; i.e., from the level of 79,951 FTE's in fiscal year 1984 to 62,945 FTE's in fiscal year 1990.

Table 2

SSA Budget Request for FY 1989 and NTEU's Recommendation

	Dollars (thousands)	FTE's (Average Positions)
Administration's Request	3,775,661	65,045
NTEU's Recommended Additions		
A. To restore positions cut in FY 1988	+66,664	+2,398
B. To restore reduction proposed for FY 1989	+92,880	+3,341
C. Sub-Total	+159,544	+5,739
NTEU's Recommended "Service Now" Initiative to Restore Caring, Efficient Service And An Effective SSA	+139,000	+5,000
NTEU total additions	+298,544	+10,739
NTEU's Recommended Budget For FY 1989	4,074,205	75,784

Table 3. Staff Additions for NTEU's "Service Now" Budget Recommendation for SSA, FY 1989
FTE's

	Field Offices	Office Hearings & Appeals	Program Service Centers	Office Central Records	Office Disability Operations	All Other	TOTAL
A. Strengthen Community-Based Service Delivery System	+2,500						+2,500
B. Improve Quality of Service							
Restore RSI & SSI Process Accuracy			+900	+20			+920
Reduce RSI & SSI Claims and Overpayment Backlogs in PSC's			+200				+200
Reduce Time Lag For Benefits Recomputation From 21 to 12 Months			+150	+20			+170
Promptly Credit Earnings And Resolve Discrepancies In Wage Reports			+200				+200
Provide Workers Regular Reports of Account And Benefit Status			+50	+10		+10	+70

Table 3 continued.

	Field Offices	Office Hearings & Appeals	Program Service Centers	Office Central Records	Office Disability Operations	All Other	TOTAL
C. Reverse The "Hollowing Out" of SSA Operations							
Restore FY 1988-89 Cuts	+3,670	+185	+1,012		+423	+450	+5,739
Improve Processing of Postentitlement Actions			+800	+10		+10	+820
D. Reduce Processing Times In Hearings and Appeals		+110			+10		+120
E. Improve Morale and Better Manage Technological Change	*	*	*	*	*	*	*
TOTAL	+6,170	+295	+3,312	+60	+433	+470	+10,739

* Resources Are Included in Items A-D. Training Budget is Increased from $125 to $170 Million.

Table 4

Table 5.2: Staff on Duty at End of Fiscal Year for Major SSA Components

Component	1982	1983	1984	1985	1986	Percent	
						1982-86	1984-86
SSA field offices	43,702	41,871	40,551	40,483	39,211	−10.3	−3.3
OHA hearing offices	4,870	4,949	4,534	4,352	4,283	−12.1	−5.5
PSCs[a]	14,390	14,563	14,154	13,495	12,279	−14.7	−13.2
OCRO[b]	5,310	4,888	5,091	5,642	4,642	−12.6	−8.8
ODO[c]	6,159	5,931	5,627	5,314	4,835	−21.5	−14.1
Total	**74,431**	**72,202**	**69,957**	**69,286**	**65,250**	**−12.3**	**−6.7**

[a] Program service centers

[b] Office of Central Records Operations

[c] Office of Disability Operations

Table 5

Staff on Duty for Major Components
(September 1986 and June 1987)

Component	Quarter ended September 1986	 June 1987	Difference	Percent change
Regional/field offices	41,080	38,461	-2,619	-6.4
Office of Hearings and Appeals	5,404	5,272	-132	-2.4
Program service centers	12,279	11,557	-722	-5.9
Office of Disability Operations	4,836	4,534	-302	-6.2
Office of Central Records Operations	4,642	5,111	+469	+10.1
All other	7,541	7,220	-321	-4.3
Total	75,782	72,155	-3,627	-4.8

Note: Includes seasonal staff on duty.

Source: General Accounting Office

Table 6

Table II.2: Awards and Disallowances Study Error Rates

Error type	Fiscal year 1985	Fiscal year 1986	Fiscal year 1987	Percent change 1985-87
Basic dollar	2.9	2.9	3.3	+14
Basic evidentiary	3.2	3.4	4.8	+50
Total basic[a]	**5.9**	**6.1**	**8.1**	**+37**
Other errors:				
Under $5	0.6	0.5	0.6	0
Potential[b]	1.4	1.8	2.2	+57
Other evidentiary	4.4	6.1	8.7	+98
Notice[c]	7.4	6.8	5.8	−22
Technical[d]	3.3	4.2	6.1	+85
Total other	**17.1**	**19.4**	**23.4**	**+37**
Grand total	**23.0**	**25.5**	**31.5**	**+37**

[a] Total basic may not equal the sum of basic dollar and basic evidentiary because, where cases have both types of error, only a basic dollar error is counted when computing the all-basic error rate.

[b] Errors that do not result in a current dollar error but could cause an erroneous payment in the future. An example is a situation in which an applicant was properly denied benefits in the current year. During the case review, the reviewer noted that earnings were not accurately recorded to the individual's account, which could affect the accuracy of future benefits.

[c] Errors that could result in an incorrect notice or a notice not being sent. The decline in notice errors is attributed to a definitional change made in mid-1986 that provided for minor notice errors being recategorized as technical errors.

[d] Errors that generally involve failure to comply with a minor procedural requirement. These errors are considered the least important of all errors recorded.

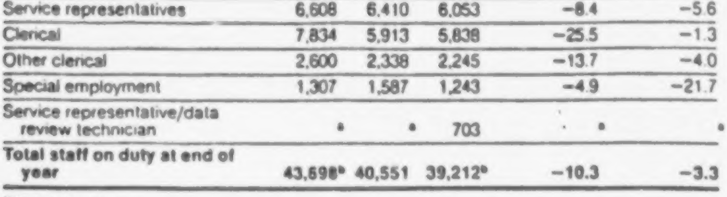
Table 7

Field Office Staff Composition

Type of position	Quarter ended September 1986	 June 1987	Difference	Percent change
Administrative	2,125	2,038	-87	-4.1
Operations supervisors	2,634	2,447	-187	-7.1
Operations analysts	405	279	-126	-31.1
Field representatives	1,088	958	-130	-11.9
Generalist claims representatives	1,468	1,671	+203	+13.8
RSI/DI claims representatives	6,333	6,193	-140	-2.2
SSI claims representatives	5,725	5,440	-285	-5.0
Claims representative trainees	289	142	-147	-50.1
Data review technicians	3,062	2,372	-690	-22.5
Service representatives	6,018	5,706	-312	-5.2
Clerical	5,837	5,164	-673	-11.5
Other clerical	2,245	2,023	-222	-9.9
Special employment	1,243	599	-644	-51.8
Service representative/ data review technician	703	1,100	+397	+56.5
Total staff on duty	39,175	36,119	-3,056	-7.8

Table 8

Table 5.7: SSA Field Office Staff Composition (Staff on Duty at End of Fiscal Year)



Type of position	Fiscal year 1982	 1984	 1986	Percent change 1982-86	 1984-86
Administrative	2,172	2,172	2,125	−2.2	−2.2
Operations supervisors	2,651	2,711	2,634	−0.6	−2.8
Operations analysts	532	467	405	−23.9	−13.3
Field representatives	1,250	1,175	1,088	−13.0	−7.4
Generalist claims representatives	1,383	1,132	1,469	+6.2	+29.8
Title II claims representatives	6,794	6,368	6,333	−6.8	−0.5
Title XVI claims representatives	5,970	6,199	5,725	−4.1	−7.6
Claims representative trainees	280	119	289	+3.2	+142.9
Data review technicians	4,317	3,960	3,062	−29.1	−22.7
Service representatives	6,608	6,410	6,053	−8.4	−5.6
Clerical	7,834	5,913	5,838	−25.5	−1.3
Other clerical	2,600	2,338	2,245	−13.7	−4.0
Special employment	1,307	1,587	1,243	−4.9	−21.7
Service representative/data review technician	[a]	[a]	703	[a]	[a]
Total staff on duty at end of year	**43,698[b]**	**40,551**	**39,212[b]**	**−10.3**	**−3.3**

[a] Not applicable.

Table 9

Program Service Centers
Staff on Duty

Program service center	Quarter ended September 1986	Quarter ended June 1987	Difference	Percent change
Northeastern	1,850	1,744	-106	-5.7
Mid-Atlantic	1,794	1,665	-129	-7.1
Southeastern	2,071	1,944	-127	-6.1
Great Lakes	2,243	2,087	-156	-7.0
Mid-America	2,365	2,218	-147	-6.2
Western	1,417	1,372	-45	-3.2
International	539	527	-12	-2.2
Total	12,279	11,557	-722	-5.9

Table 10

PSC	End of fiscal year					Percent change	
	1982	1983	1984	1985	1986	1982-86	1984-86
North Eastern	2,299	2,367	2,244	2,103	1,850	−19.5	−17.6
Mid-Atlantic	1,977	1,986	2,010	1,929	1,794	−09.3	−10.7
South Eastern	2,433	2,406	2,317	2,228	2,071	−14.9	−10.6
Great Lakes	2,620	2,600	2,545	2,457	2,243	−14.4	−11.9
Middle America	2,730	2,766	2,695	2,590	2,365	−13.4	−12.2
Western	1,772	1,863	1,725	1,600	1,417	−20.0	−17.9
International	559	575	618	588	539	−3.6	−12.8
Total[a]	14,390	14,563	14,154	13,495	12,279	−14.7	−13.2

[a] Excludes central office support staff.

Source: General Accounting Office

Table 11

Office of Hearings and Appeals
Hearings Office Staff on Duty

Region	Quarter ended September 1986	Quarter ended June 1987	Difference	Percent change
Boston	182	163	-19	-10.4
New York	579	555	-24	-4.1
Philadelphia	439	443	+4	+1.0
Atlanta	898	860	-38	-4.2
Chicago	776	755	-21	-2.7
Dallas	463	438	-25	-6.6
Kansas City	170	193	+23	+13.5
Denver	101	102	+1	+1.0
San Francisco	539	572	+33	+6.1
Seattle	136	133	-3	-2.3
Total	4,283	4,214	-69	-1.6

Table 12

Hearings Office Staff Composition
(September 1986-June 1987)

Position	September 1986	June 1987	Difference	Percent change
Administrative law judge	691	653	-38	-5.5
Decision writer	683	653	-30	-4.4
Hearings assistant	870	832	-38	-5.7
Clerical	1,480	1,480	0	0
Management	153	139	-14	-9.2
Total	3,877	3,757	-120	-3.1

Note: Figures reflect only full-time permanent employees in hearings offices and do not include regional office staff.

Source: General Accounting Office

STATEMENT OF THE AMERICAN LIVER FOUNDATION

I am Yvonne Roberts -- 29 years old and I've been struggling to cope with the destruction of my liver and my life by a virus that attacked me when I was 15 years old. I am living on borrowed time, borrowed organs and borrowed money.

I don't know how I caught non-A, non-B hepatitis . . . nor do the doctors. Four years ago, I had my first liver transplant. My recovery was slow and I struggled to adjust to my new liver.

The quality of my life deteriorated over the next three years and I had to have another liver transplant last November. I also had to have my spleen removed after my second liver transplant because of internal bleeding, a complication of my transplant. The medication I must take to keep from rejecting my liver has destroyed 80% of my kidneys and I am now on the waiting list to receive a kidney transplant.

Another virus, called cytomegalovirus (CMV), has attacked my system and I've spent the last 10 months in and out of the hospital while doctors have tried experimental treatments in an effort to improve my health so that I will be strong enough to undergo more surgery. Currently, I am in the long line of patients waiting for recycled organs. I pray that a kidney will be found for me real soon.

My hospital bills since my first transplant have exceeded $500,000. My family has spent another $200,000 to be with me during this entire process. They have sacrificed a great deal to help me stay alive.

Last year, 1200 liver transplants were performed at an average cost of $250,000 for medical expenses alone. That's $300 million spent to try to restore and rebuild these lives. 400 of those patients didn't make it. I am one of the lucky survivors, but I'm not out of the woods yet.

Over the past 14 years, an estimated 1,350,000 people have been infected by the non-A, non-B hepatitis virus. 25% of those folks . . . including me . . . developed cirrhosis. Last year, an estimated 90,000 people became infected with non-A, non-B hepatitis. 90% of them were infected through a contaminated blood transfusion . . . because there is no specific test to identify this virus in donated blood.

Maybe it was:

- a teenage victim of an accident;
- a mother who ran into trouble delivering her baby;
- a corporate executive who required a coronary bypass, prostate surgery, or removal of his gallbladder.

10%-12% of the 3 1/2 million people who received blood or blood products last year became infected with non-A, non-B hepatitis.

> A prominent gastroenterologist's wife recently had twins. She began to hemorrhage after the first baby was born and she was rushed to surgery for a Caesarean section. She was desperately in need of three pints of blood. Because of their fear of acquiring non-A, non-B hepatitis, she and her husband opted not to have her receive the blood transfusions. Her recovery was greatly prolonged due to the reality that her life could be jeopardized by taking that gamble.

My family and I . . . and thousands of other people whose lives have been literally destroyed . . . ask "Why hasn't a test been developed to screen all blood for this treacherous virus?"

I'm told that last year less than $70 million was spent on liver research at all the Institutes of health . . . compared to an estimated $300 million spent on liver transplant surgery.

I implore you to increase research efforts to find ways to prevent non-A, non-B hepatitis -- and other liver diseases. I don't want others to have to go through the agony and uncertainty I am experiencing. I want to live. I want to work and get married and have a family. But I am a victim -- and helpless, at this point, to find a better solution.

You, gentlemen and ladies, hold the purse strings to wellness for 90,000 potential new victims of non-A, non-B hepatitis each year. Every patient who receives a blood transfusion is playing Russian Roulette when it comes to non A, non B hepatitis. Who will be the next unsuspecting victim? It could be you or a loved one. Tragically, there will be thousands of unsuspecting mothers, fathers or children in every state in the country.

Thank you for letting me share my story with you.

STATEMENT OF THE ASSOCIATION FOR HEALTH SERVICES RESEARCH

My name is Judith Lave and I am President of the Association for Health Services Research, a national organization dedicated to promoting, strengthening, and improving health services research in this country.

Just 3 years ago, Mr. Chairman, national health expenditures totaled $355 billion. Last year, that amount had grown by 40 percent, to approximately $500 billion. What is more, the Health Care Financing Administration is now projecting that by the year 2000, health care spending will more than triple, to a staggering $1.5 trillion.

Accompanying the rapid increase in costs are a host of issues, most of which impact one way or another on the important work of this Subcommittee.

Is the Medicare system jeopardizing the quality of care being provided to our nation's elderly?

How can the health care system best respond to the growing need for long-term care by the elderly and the disabled?

And what steps should be taken to ensure that those living in rural areas receive the health care to which they are entitled?

Lastly, with the total direct costs of AIDS expected to exceed $8 billion by 1991, what measures can we take now to ensure that we have in place the most cost-effective mechanisms for providing care to the target population?

Mr. Chairman, these are not simply academic questions. They are some of the very real and very critical issues confronting this and subsequent sessions of Congress. Whether or not Congress will be able to make informed decisions about these issues will depend largely on the information that is generated through health services research. Whether or not Congress is able to develop and adequately test alternative approaches to these problems will depend on the investment Congress is willing to make in health services research.

Unfortunately, Mr. Chairman, there is a tremendous disparity between how much this country spends each year on health care versus how much we invest in exploring and evaluating new ways of providing cost-effective, high-quality care to our citizens. The fact of the matter is that 0.04 percent of the total health budget is spent on health services research.

How can health services research make a difference?

Among other things, it can help us achieve that precarious balance between controlling costs and ensuring the availability of high-quality care.

Under the Medicare system, for example, physicians are reimbursed for procedures rather than results. Hospitals are reimbursed on the basis of an admission for a particular diagnosis rather than for beneficial outcomes. Very little is known about the relative risks or benefits associated with many of the so-called standard procedures used by physicians and hospitals.

Every year, new studies show that what was commonly accepted practice in some areas has now been proved to be useless, or perhaps even harmful. Other studies have shown that the kinds and costs of hospital treatment in a community are more related to the numbers of physicians and their specialties than to the health of the population.

One specific example of the difference outcomes research can make relates to a research project currently underway at George Washington University. Researchers there are now developing a tool to improve the quality of care delivered in an intensive care unit, while at the same time reducing the costs of that care. This tool will allow us to accurately measure the severity of illness of acutely-ill patients, as well as compare the cost and outcome of intensive care units at various hospitals.

Research has demonstrated that the number of acutely-ill patients an ICU saves is directly related to the coordination of care in that unit. This study has also shown that the quality of intensive care varies greatly from hospital to hospital. If applied on a nationwide basis, the findings of this research could result in saving as many as 10,000 lives.

This is just one striking example of what health services research can tell us. I can assure you that there are many more.

Years ago, industry learned that research spent on what works and what does not is one of the best investments one can make. It is time we learned the same lesson when it comes to health care in this country. It is time for us to improve our tools of decisionmaking.

If we choose to ignore that challenge for the sake of relatively small, some would say inconsequential budget savings, we jeopardize every facet of our health system, including the important work of the National Institutes of Health. Our success in meeting new threats to health such as the emerging AIDS epidemic will count for little unless we have in place the mechanisms necessary to channel the products of medical research into a responsive, cost-effective health delivery system.

Looking at it from another perspective, Mr. Chairman, failing to invest in health services research in the long run threatens this Subcommittee's ability to provide adequate funding for NIH and other discretionary health programs.

Recommendations

For the reasons I have stated, our Association urges this Subcommittee to strengthen the federal commitment to health services research by-

- o appropriating $30 million for the National Center and approving language authorizing the transfer of funds required to support the National Medical Expenditure Survey;

- o providing $7.5 million to fully-fund the National Center's outcomes research program;

- o appropriating $45 million for HCFA's Office of Research and Demonstrations; and

- o expanding support for services systems research by the National Institute of Mental Health.

Thank you, Mr. Chairman. I would be glad to answer any questions you may have.

STATEMENT OF THE AMERICAN GAS ASSOCIATION

The American Gas Association (A.G.A.) is a national trade association comprised of some 250 natural gas distribution and transmission companies serving over 166 million natural gas consumers throughout the United States. We appreciate this opportunity to present our views to thesubcommittee in support of the Low-Income Home Energy Assistance Program (LIHEAP).1/

A.G.A. member companies are deeply committed to meeting the energy needs of all of our consumers, including our low-income consumers. A.G.A. has long supported federal energy assistance programs such as LIHEAP and the Department of Energy weatherization program. In addition to supporting federal funding efforts, A.G.A.'s member companies have contributed significantly to low-income energy assistance.

We in the natural gas industry urge this subcommittee to take the lead in restoring LIHEAP funding at least to the FY 1987 level of $1.825 billion. The current FY funding for LIHEAP is $1.53 billion and, as you are aware, for FY 1989, the Administration proposes only $1.187 billion for LIHEAP.

We realize it is a very difficult federal budget year. But as this subcommittee knows, LIHEAP has already taken more than its share of funding cuts. LIHEAP funding was decreased by 9 percent in FY 1987 compared to FY 1986 and 16 percent in FY 1988 compared to FY 1987.

If approved by Congress, the Administration's proposal would result in a cut in assistance by 22 percent compared to current levels and 35 percent from 1987 levels. Certainly, this action would severely restrict our ability to continue to meet the needs of the low-income consumer. Reduced benefit amounts and more stringent eligibility guidelines would occur, therefore further reducing the effectiveness of these programs despite a continuing need.

A.G.A. is not implying that the burden of the low-income consumers' needs rests solely on the shoulders of the federal government. The states and the private sector also have a responsibility and do contribute significantly to the needs of these consumers. A.G.A. member companies have developed several innovative and effective programs in this area.

A.G.A. member companies are also actively supporting weatherization programs for the low-income household. Weatherization represents the long-term solution for the energy cost situation that faces many low-income consumers.

Since the early 1980s, many A.G.A. member companies have created and helped finance private fuel fund programs and weatherization projects in an effort to supplement LIHEAP and other federal programs. In fact, to date, A.G.A. member companies have raised about $10 million through customer and matching stockholder contributions in an effort to ease the burden of energy costs on our low-income customers. But these programs can only supplement, not supplant, an adequately funded LIHEAP.

In addition, A.G.A. established a Fuel Subsidies Subcommittee, which is composed of gas industry executives, and which monitors and offers guidance to the industry on federal, state and local energy assistance issues. Indeed, the gas industry's concern about the impact of energy costs on low-income customers is ongoing and predates LIHEAP.

Despite the efforts of A.G.A. member companies' fuel fund programs and other financial support from the private sector, the need for adequate federal funding of LIHEAP remains imperative.

LIHEAP FUNDING CUTS AFFECT ALL ENERGY CONSUMERS

The lack of adequate funding will affect more than the low-income households, because adequate funding of LIHEAP plays an import role in keeping utility rates stable for all consumers.

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Low-income consumers who do not receive energy assistance, in many cases, simply cannot pay the full amount of their utility bills. With the mandated and voluntary moratoria on utility service terminations in most states during the winter months, these consumers continue to receive gas service. We attempt to work out a manageable plan for these consumers. However, if not successful, the cost of providing gas service without payment is ultimately considered part of a utility's costs of service and later becomes a burden that is borne by all utility consumers.

There are virtually millions of consumers who are on the fringe of LIHEAP eligibility. Often referred to as the "working poor", they are currently able to meet their energy costs without LIHEAP. However, an increase in energy costs could place these households in the same inability to pay situation that faces LIHEAP-eligible households today.

ADEQUATE FUNDING FOR LIHEAP

To millions of low-income consumers, LIHEAP is a badly needed safety net. Federal statistics show that the average LIHEAP recipient has about $10 a week remaining after paying for housing, food and home energy. Furthermore, studies have repeatedly shown that low-income families pay a much greater share of their incomes for energy costs than do other families. According to recent Department of Health and Human Services (HHS) data, compiled in the mid-1980s, on low-income households' energy consumption, households with incomes below 125 percent of the poverty level spend approximately four times the amount of their income for energy, than the remainder of the households in this country.[2]

Presently, only a small portion of these consumers' total energy costs is covered by LIHEAP.[3] In its 1988 report, the Northeast Midwest Coalition indicated that for

1987, LIHEAP funds covered only 19.5 percent of the energy costs for eligible households.[4] Moreover, according to statistics provided by HHS, only between 29 and 37 percent of all eligible households received LIHEAP funds in FY 1986.[5] The average LIHEAP benefit is about $200 a year, versus about $1,000 in energy costs.

While there always are going to be consumers who are manipulating the system to avoid paying their bills, there are many more consumers out there who are making an honest effort with their financial responsibilities. LIHEAP is a great assistance to them.

STATE SUPPLEMENTS ARE ONLY TEMPORARY

Because of the federal budget cuts in LIHEAP, many states have supplemented their LIHEAP programs with oil overcharge monies in order to continue to help the maximum number of low-income consumers. But this practice removes funds previously committed to weatherization programs. Without significant weatherization efforts, the ability of the low-income households to reduce their energy needs no longer exists. Obviously, this can only be a temporary solution.

Finally, Congress should note that the impact of oil overcharge funds resulting from court decisions in U.S. v. Exxon and Stripper Well[5] is also diminishing. While these monies were meant to supplement rather than supplant fuel aid programs, there is only approximately $1 to 1.5 billion yet to be collected by the states. As of December 1987, states had received about 73 percent of the penalties paid, assigning these overcharge funds for weatherization and not for LIHEAP.[6] Therefore, the existence of oil overcharge funds should have no bearing on the amount Congress appropriates for LIHEAP.

CONCLUSION

Certainly, both the private and public sector must be prudent managers of spending. However, assistance is needed for the low-income consumer who is struggling to make ends meet. There is a limit as to what assistance the state and local governments and business can do in order to supplement the federal budget cuts of the LIHEAP program.

We must all continue to work together to affect change. Therefore, A.G.A. respectfully urges this subcommittee to support our recommendation to restore LIHEAP funding closer to the FY 1987 funding level.

FOOTNOTES

1/ 42 U.S.C. §§ 8621 et seq. (1983).

2/ Northeast Midwest Institute, Narrowing the Gap, The Energy Needs of the Poor and Federal Funding (January 1988), at 25.

3/ See American Gas Association, Providing Essential Energy Services to Low-Income Customers pp. 7-9 (1985); Northeast Midwest Institute, Narrowing the Gap, The Energy Needs of the Poor and Federal Funding (January 1988); National Consumer Law Center, Homes Without Heat: A Nationwide Study of Disconnected Natural Gas Users, at 16-17 (1984); National Consumer Law Center, Out in the Cold, at 3 (1983);

4/ Narrowing the Gap, supra, at 24.

5/ U.S. v. Exxon Corp., 561 F. Supp. 816 (D.D.C. 1983), aff'd. 773 F.2d 1240 (TECA 1985), cert. den. 88 L.Ed. 2d. 926 (January 27, 1986); In Re Department of Energy Stripper Well Exemption Litigation, 578 F. Supp. 586 (D. Kan. 1983; Settlement agreement approved on 7/7/86 (M.D.L. No. 378)).

6/ Narrowing the Gap, supra, at 79.

STATEMENT OF THE MOREHOUSE SCHOOL OF MEDICINE

Mr. Chairman and members of the Subcommittee, I am Louis W. Sullivan, M.D., President of The Morehouse School of Medicine in Atlanta, Georgia, the first predominately black medical school to be funded in the United States in the 20th Century. It gives me great pleasure to submit for the Hearing Record my views with respect to FY '89 funding for health professions training, biomedical research and student and institutional assistance.

Our institution, and the students who attend our school, rely heavily upon federal institutional and health professions programs. The goal of our institution is to increase the number of black and other minority health professionals in the nation. Our efforts are, of course, profoundly affected by your Subcommittee's decisions.

Mr. Chairman, your Subcommittee has played a very significant leadership role in insuring that adequate resources are provided to the federal programs of great concern to The Morehouse School of Medicine, and we want you to know we very deeply appreciate every consideration you and the other members of the Committee, together with the excellent assistance provided by your staff, have given to these programs.

FY '89 President's Budget

I am concerned that the President's budget again recommends that funding for health professions training programs be severely reduced, and administered as a block grant. This shortsighted plan would set back significantly the tremendous progress made over the past several years.

The President's proposed budget for education programs is, for the first time in years, somewhat realistic. Student aid in the form of Guaranteed Student Loans appear to be adequately supported, but we are concerned that increases in the amount of funds requested not be at the expense of other important student aid programs. The same is true for institutional support. We are very encouraged that support for strengthening Historically Black Colleges and Universities is maintained.

Health Professions and Student Aid

The very difficult and hard fought gains made in black enrollment and graduates of health professions education programs peaked in the mid-seventies. In recent years, the applicant pool of blacks and other minorities who are seeking health professions careers has declined significantly. Four major factors that have led to the decline are (1) the continued lack of educational preparedness of these groups; (2) the attraction of these young students to other less rigorous, and more financially rewarding professions; (3) large debts incurred by minorities who pursue health professions careers. For example, the average debt in 1987 of a student graduating from The Morehouse School of Medicine was $49,000, compared to $32,000 in 1985. These numbers are staggering to all of us -- but they are overwhelming to black and hispanic students from poor and lower income families; and, (4) lack of knowledge of, and access to, the financial resources necessary to pursue a medical career.

Debts of this magnitude, if they continue, may virtually preclude the graduates of our schools from practicing

- as primary care physicians in poor, medically underserved areas - that need physicians but cannot attract them.

Federal Health Professions Programs have had a tremendous impact on efforts to supply the nation with qualified health professionals. However, minority health professionals in medicine continue to be disapproportionally low. While blacks represent approximately 12 percent of the U.S. population, less than three and a half percent of the nation's physicians are black.

One mission of The Morehouse School of Medicine is to encourage our graduates to establish practices and serve in areas with high percentages of minorities. Many of these areas are also health manpower shortage areas, so increasing the number of minorities in the health professions is a good investment for the nation.

Mr. Chairman, unless health professions and student aid programs are significantly expanded for minorities, the number of minorities participating in medicine will remain tragically low. As recognized by the HHS Secretary's Task Force Report on Black and Minority Health, the health status of minorities is likely to improve with an increase in the number of minority health professionals. Your Subcommittee has demonstrated tremendous support in achieving this goal and Mr. Chairman, we greatly appreciate it.

Higher Education Institutional Programs

Institutional programs for strengthening Historically Black Colleges and Universities are very important to the continued development of many institutions that train a great number of blacks and other minorities. The strengthening grant programs for Historically Black Graduate Institutions are designed to establish or strengthen the physical plants, financial management, academic resources, and endowments of HBCUs. A further use of the resources for the establishment of an endowment development office or to increase contributions from private sources is a very positive aspect of the program. The strengthening program for Historically Black Graduate Institutions is having a significant positive impact on our institutional capability to achieve these goals. As mentioned earlier, we are very pleased that the President's budget proposal includes funding for this program, and recommend that the Committee give consideration to fully funding these important programs in FY '89.

One part of Title III is deserving of particular attention. Section 326 authorizes the Secretary of Education to award program grants to post graduate institutions that are "... making a substantial contribution to the ... medical, dental, veterinary or other graduate educational opportunities for Black Americans." The Morehouse School of Medicine is making a "substantial contribution."

Our institution is deeply appreciative of the actions taken last year that provided $10 million in funding for Section 326. Given the demonstrated decline in and concern about the number of blacks pursuing medical degrees, upon which I touched earlier, it is essential that increased funding for Section 326 be a high priority in Fiscal Year 1989.

Section 326 monies are used to fund the purposes enumerated in Section 323. In addition, institutions, in order to maximize the amount they may receive under Section 326, must also raise an equivalent amount from non-Federal sources. Increasing contributions from alumni, the private sector, and the development of institutional endowments are worthy goals promoted by the funding authorized under Section 326.

I am pleased to be able to report to you that as a direct result of your support for this Section and its predecessors, The Morehouse School of Medicine has been able to make great strides. Founded in 1975 as the first predominately black medical school to open in the 20th Century, Morehouse was the first school to receive funding under this program (in 1982). With the assistance provided to Morehouse under Section 326, we have been able to accomplish the following over the past six years:

1. Development from a two-year medical school in the basic medical sciences to a four year, fully accredited medical school, chartered by the State of Georgia to award the M.D. Degree.

2. Significant development of our faculty and programs in the basic medical sciences; and early progress toward development of our faculty and programs in the clinical medical sciences.

3. Expansion of our medical curriculum and academic support system.

4. Enhancement of our institution's research capability. Our young faculty has been successful in competing for research grants from the NIH, NSF, and other sources.

5. Established a preventive medical/public health residency program, and a family practice residency program.

6. Early development of educational programs designed to prevent alcohol and drug abuse, cardiovascular diseases, AIDS, teenage pregnancy, cancer and other preventable conditions.

7. Established continuing Medical Education programs for practicing physicians.

Obviously, we are most proud of our graduates and their accomplishments. Morehouse School of Medicine students have a very high pass rate on the national Board Examinations. In addition, our graduates have received appointments in residency programs at a number of the nation's oldest and most prestigious university-affiliated hospitals. Three of our graduates became chief residents on their services. Some 75% of our graduates are doing post-graduate training in primary care fields; 70% of our graduates are practicing in medically underserved inner cities and rural areas.

I have offered the above as a Progress Report on the accomplishments of The Morehouse School of Medicine, which were made possible with grants from Section 326. Section 326 is a particulary good investment for the nation, and deserves a very high mark. The fact is that without Section 326 funding, these accomplishments would not have occurred.

However, much remains to be done. We plan to expand our entering class size from 32 to 64 over the next five years. Full development of our educational, service and research capabilities must continue. For this, additional support through Section 326 is essential.

Mr. Chairman, it is our request to you and the Committee that funding for Section 326 be increased to $15 million for FY '89. This is essential if we are to continue to make the progress we have over the past few years, and if the other institutions which are now included in this program are to realize their full potential.

Minority Research Initiatives

The Research Centers at Minority Institutions Program, introduced by Congressmam Louis Stokes, and supported by you and your Subcommittee, has been a very valuable mechanism for the continued development of the research capability of The Morehouse School of Medicine, especially for the study of diseases and health status factors that are more prevalent among blacks than in the general population. One example of this is the initiative taken by the Division of Research Resources to utilize a portion of the NIH AIDS funding to develop programs at minority institutions that will accelerate the ability of these schools to study risk factors for AIDS, and to develop prevention techniques. The RCMI directors met recently to plan for program development in this area. Mr. Chairman, the RCMI program has allowed The Morehouse School of Medicine to obtain state-of-the-art research equipment and supplies, hire research faculty to complement existing staff, provide faculty research development programs, create research training opportunities for undergraduate and graduate students, and fortify institutional services that support research. Most importantly, RCMI has served as a major stimulus in the ability of our institution to compete for more traditional sources of research funding. In order to strengthen the RCMI program, we recommend a FY '89 funding level of $17 million for RCMI.

I would also like to encourage your Subcommittee to explore how specific NIH Institutes could supplement RCMI programs with research funds provided by your Subcommittee, similar to the AIDS effort, and related to the disease specific missions of the individual institutes. I believe that integration of resources into these existing programs could have a major impact on our knowledge of factors contributing to the gap in health status between blacks and whites.

The Morehouse School of Medicine also recommends that NIH guidelines be changed to include RCMI funds received by our institution when making Biomedical Research Support Grants (BRSG). This would be consistent with traditional NIH grant mechanisms and policy.

The Morehouse School of Medicine is also very supportive of the Minority Biomedical Research Support programs (MBRS), and the Minority Access to Research Careers Program (MARC). It is very important, in our view, that the focus of the MBRS program be shifted back to its original emphasis of supporting minority students and faculty at minority schools, rather than the current situation, wherein a major portion of MBRS funds are being awarded to majority schools. We encourage your Subcommittee to provide adequate resources to fully fund the MBRS programs. Further, we believe a review of the stipend levels for these programs is due.

As you know, Mr. Chairman, the Authorizing Committees are considering a rewrite of the NIH statutory authority this year. Among the proposals being considered is a general facility construction authorization that has been missing for years. The state of biomedical research facilities in this nation is precarious and we support the inclusion of an authority for construction of extramural biomedical research facilities.

The Morehouse School of Medicine recognizes the importance of a federal facility construction system that utilizes peer review based on institutional capabilities and scientific merit. We also urge that some federal resources be awarded to institutions based on the disperate health status of various segments of the nation's population groups, and the needs and capabilities of the institutions that can have the greatest impact on addressing those needs. The historically black health professions schools in this nation are demonstrating an emerging excellence and capability to train physicians, faculty, and study disorders that disproportionately affect minorities. Therefore, we believe that, when considering Federal resources for construction and renovation of facilities, criteria should be developed that support these important and unique capabilities of minority health professions schools.

Funding for construction of research facilities at institutions which demonstrate emerging excellence in biomedical and behavioral research could be considered under the following critiera:

A. An institution which carries out research and training programs which have a special relevance to a health problem, concern, or unmet health need in the United States.

B. An institution which has already demonstrated a commitment to enhancing and expanding its research productivity.

C. An institution that has been productive in research and research training in the face of significant challenges such as the underrepresentation of minorities in the health sciences; research on the disparity of the health status of a large significant segment of the population.

D. An institution that has a plan for research advancement, and the ability to carry out such a plan.

The Morehouse School of Medicine supports the funding recommendation of $8.5 billion for the NIH, in coordination with the Ad Hoc Committee for Medical Research Funding.

The Centers for Disease Control

Mr. Chairman, in August 1987, The Morehouse School of Medicine, as a member of the Association of Minority Health Professions Schools, began discussions with Dr. James Mason, Director of the federal Centers for Disease Control (CDC) and his staff, concerning the development of initiatives by CDC to address the higher mortality and morbidity rate in the nation's black population, as outlined by the DHHS Secretary's Task Force on Black and Minority Health. With the cooperation of Dr. Mason, and his staff, the institution is working to develop a closer liaison with CDC in this national effort.

I am also pleased that CDC has funded the development of three prevention centers at academic institutions for health promotion efforts, though none of these is yet based at a minority health professional school.

I respectfully urge your subcommittee to provide full Funding for the programs at the Center for Disease Control, so that The Morehouse School of Medicine, and others, can work more effectively with CDC in its efforts to improve the health status of the nation's citizens, including its black and other minority population groups.

Mr. Chairman, thank you for the opportunity to submit for the Hearing Record the views and recommendations of The Morehouse School of Medicine. Again, we appreciate the support your subcommittee has provided to the programs of great interest to our institution.

STATEMENT OF JOAN PINCHUK, REFUGEE COORDINATOR, DEPARTMEN OF COMMUNITY AND SENIOR CITIZENS SERVICES, COUNTY OF LO ANGELES

Mr. Chairman and Members of the Subcommittee, I am Joan Pinchuk, Los Angeles County Refugee Coordinator and Director of the Refugee Targeted Assistance and Employment Services Programs in Los Angeles. I request your support in restoring $48 million for Targeted Assistance (TA) and $71 million for Employment Services (ES) in the 1989 Fiscal Year budget.

The funding of these programs is most needed and warranted because it will provide employment and English language training for refugees/entrants to help them become self-sufficient and reduce their dependency on welfare. The specific reasons for requesting the restoration of funds to the 1986 funding levels are as follows:

-- California, in particular Los Angeles County, has a disproportionately high concentration of refugees compared to the rest of the nation. Los Angeles County now receives 25% of all refugees initially resettled in this country by the US State Department. California receives 45% of all refugees coming to the USA. This is primarily due to the large increase of Soviet Armenians leaving the USSR, of which 90% are being resettled in Los Angeles by the U.S. State Department.

-- The Los Angeles County Refugee Targeted Assistance Program has proven to be successful, since its inception, by placing 7200 refugees in unsubsidized jobs thereby reducing or eliminating their welfare dependency.

-- The Administration has proposed to unfairly shift the costs of refugee resettlement and programs for self-sufficiency to local governments by proposing the reduction of refugee service funding nationwide, from $119 million in 1986 for TA and ES to $64 million for both programs in 1989.

-- Los Angeles County does not have the resources to fill the gap that will result if all the refugee budget cuts proposed by the Administration are adopted.

I would like to provide the following information on the above points:

LOS ANGELES COUNTY HAS LARGEST REFUGEE POPULATION IN THE USA:

Of the total refugee admissions to the United States, Los Angeles County currently receives 25% of all refugees. This could amount to a minimum of 20,000 refugees a year initially resettled in Los Angeles County, over a 100% increase since the first of last year. California is presently receiving 45% of all refugees.

The Secretary of State in consultation with Congress raised the refugee admissions ceiling for fiscal year 1988 from 68,500 to 83,500 this past May so as to accommodate the admission of up to 15,000 refugees from Eastern Europe and the Soviet Union.

The State Department advises that up to 12,000 Soviet Armenian refugees may enter the country during FY 1988. About 10,000 of these are expected to settle in Los Angeles County.

Thus far during the first eight months of FY 1988, over 25% of the refugees who have entered the U.S. have been resettled in Los Angeles County, up from 15% in FY 1987 and 10% in prior years.

TARGETED ASSISTANCE AND EMPLOYMENT SERVICES HAVE PROVEN SUCCESSFUL IN PLACING REFUGEES IN UNSUBSIDIZED JOBS:

For the four years that Targeted Assistance has operated in Los Angeles County, the following results have been seen:

1. Refugees have been diverted from seeking and receiving public assistance.

   Over 4800 adult refugees who were not on welfare but who were at or below the poverty level were placed in jobs that supported themselves and their family. Consequently, persons were diverted from the welfare system resulting in the substantial savings of millions of dollars.

2. Refugees' welfare benefits were terminated or reduced due to their placement in unsubsidized employment.

   During the past four years, approximately 2400 refugee welfare cases or over 6200 refugees have had their welfare check terminated or reduced as a result of their obtaining employment through the Targeted Assistance program.

The job retention rate of the refugees obtaining unsubsidized employment has also proven quite high. It was found that close to 70% were still working 90 days after placement. Ninety days consecutive employment has been the criteria for success in Targeted Assistance whereas other employment programs only follow the participants' job progress for 30 days.

3. The program has cost less than $3500 per refugee placed in employment.

Each refugee who received counseling and training that ultimately resulted in a job placement, cost less than $3500 per refugee. This compares to the cost of approximately $8800 a year in welfare benefits for a family of three where the head of household has no job. In addition, other mainstream programs that do not primarily serve difficult-to-place persons may cost $4400 plus, per person placed. The refugee participants served by Targeted Assistance have numerous barriers to employment, such as:

(1) One quarter (1/4) have fair to no English at all;

(2) Over one third (1/3) had dropped out of school or have no education to speak of;

(3) One third (1/3) have large families of four or more, and

(4) Over one half (1/2) have been in this country less than three years.

Thus, the cost of the Targeted Assistance Program and Employment Services has been most economical.

COSTS FOR SERVICES TO REFUGEES ARE UNFAIRLY BEING SHIFTED TO LOCAL GOVERNMENTS

The funds for the Refugee Employment Services and Targeted Assistance Programs have been proposed to be cut by the Administration. This places a burden on local governments to help this new population become self-sufficient and complete the federal resettlement process. With such drastically reduced funding, resources will not be available and this new population may have to resort to receiving welfare to support themselves and their family rather than obtaining the specialized help they need to be self sufficient.

Additionally, the Administration has reduced the time eligibility of the refugee population to 24 months, one year less than authorized by the Refugee Reauthorization Act, again shifting refugee welfare costs to local governments.

HHS/ORR has also based their 1989 request for TA and ES, on refugee admissions of only 51,000, even though 83,500 will be admitted in FY 88 creating a dramatic service demand in FY 89.

Because in FY88, HHS/ORR's budget request was based on unrealistically low cost assumptions, a critical shortfall in funding and services has been created. If funding shortfalls continue into FY 1989, the effectiveness of the Federal Refugee Resettlement Program will be in serious jeopardy causing a hardship on local government and more importantly our "New Americans".

Thank you.

STATEMENT OF MORDECAI P. BLAUSTEIN, M.D.

Mr. Chairman and members of the Subcommittee, I thank you for the opportunity to testify on the Fiscal 1989 NIH budget on behalf of more than 5,000 scientists in the Biophysical Society. I am Mordecai Blaustein, Chairman of the Department of Physiology and Scientific Director of the Hypertension Center at the University of Maryland School of Medicine, and a member of the Biophysical Society.

First, my colleagues and I thank you for your past support of the NIH which has led to enormous advances in biomedical knowledge. We are especially greatful for your recent support of funds for graduate education in Biophysics.

I'd like to make two points: One concerns the support for training; the second concerns research grants.

I am Director of a new NIH-funded Training Program, and I assure you that one of our highest priorities is to educate the next generation of biomedical scientists. But we have a manpower crisis: In 1972 NIGMS was able to support 4,042 pre-doctoral trainees, but the Institute had funds for only 1,717 pre-doctoral trainees this year. Our own program supports a total of only five traineees for the five-year curriculum: that's only one trainee per year! Because of the shortage of funding, we are losing the most capable college graduates to other fields: and, only with more capable thinkers will we be able to make more breakthroughs. As La Rochefoucauld said, "Although men flatter themselves with their great actions, they are not so often the result of great design as of chance." And "Chance," said Pasteur, "only favors the prepared mind."

My second point concerns the inadequate number of individual investigator-initiated research grants, and the erosion in the amount of these awards due to administrative cuts called "downward negotiations". I, myself, received a 10% cut in an NIH grant this year: that is 10% below the peer review recommendation to enable me to carry out the research.

The importance of non-targeted, investigator-initiated research grants is illustrated by my own experience. Starting with basic research on nerve and muscle of marine invertebrates, my colleagues and I unexpectedly discovered a key relationship between sodium and calcium metabolism. This led me to develop what is, today, the most widely quoted theory about how excess dietary salt causes high blood pressure in man. This, in turn, led to the discovery of a new hormone that may be the critical link between salt and high blood pressure. One of my colleagues at Maryland has just purified this hormone from human plasma, but he has two competitors, and both are Japanese. The race is now on to determine the structure of this hormone. Given the NIH support that led to the initial breakthroughs, we certainly hope that any patent rights that result from this research will be issued first in the United States.

The colleague at Maryland who made this breakthrough is an Englishman who came here to work because of inadequate research funding in Great Britain. We cannot permit that to happen in the United States.

Therefore, we join the Ad Hoc Committee for Medical Research Funding in recommending a Fiscal 1989 appropriation of $8.2 billion for NIH, including AIDS funding, that will support 7,400 new and continuing research grants as well as the 11,000 trainees recommended by the Institute of Medicine. Only with a cadre of well-trained scientists and an adequate knowledge base can we be prepared to tackle such critical problems as the current AIDS crisis.

Senator Chiles, I thank you for your attention. My colleagues and I greatly appreciate your very strong support of the NIH. We regret that you won't be here next year to continue your efforts.

STATEMENT OF THE BIOPHYSICAL SOCIETY

Mr. Chairman, and Members of the Subcommittee, it is truly a great honor to have the opportunity to testify before you on the FY1989 appropriations for the National Institutes of Health.

I am Mordecai Blaustein, Professor and Chairman of the Physiology Department and Scientific Director of the Hypertension Center at the University of

Maryland at Baltimore. I am here today representing the membership of the Biophysical Society-- over 5,000 men and women scientists, whose research, scholarly and academic activities are deeply affected by the decisions this Subcommittee makes regarding the budget for the National Institutes of Health.

Over the years, the Members of this Subcommittee have shown time and again, their unfailing commitment to health and basic research. Indeed, it has been your vision and your support for the National Institutes of Health that have made NIH and our biomedical research infrastructure a model for the rest of the world.

Mr. Chairman, as working scientists we deeply appreciate all your Committee's efforts on behalf of NIH. The decisions you are faced with are, indeed, difficult, particularly in light of the fiscal pressures our country is experiencing. We fully understand that federal dollars are extremely tight, and that this Subcommittee, and the Congress as a whole, have many pressing and deserving needs.

Nevertheless, we would be remiss as scientists, and as concerned citizens, if we did not come to you to express our views and to join our voices with those present today who believe that it is imperative to increase the NIH budget in order to maintain the excellence for which it is noted.

While writing this testimony it was rather difficult, I must confess, to think of arguments which you may not have heard or may not have used yourself in support of NIH and the extramural programs. All of these arguments are as valid today as they were the first time they were made - the importance of patient care, new cures for diseases, exciting new research with biomedical applications, etc. After giving it some thought, I decided that perhaps the best contribution I could make was to share with you my own experiences and my own concerns as I am sure these will reflect, in many ways, the experiences of my colleagues.

There are two areas I would like to mention specifically: the need for enhanced training support, and the need for a growing individual investigator-initiated grant program.

Training is, in our view, one of the most important and critical investments our country can make in its future. The Biophysical Society membership, for example, was delighted to learn that the NIH recently established a much needed and welcomed training program in the biophysical sciences. This training program has opened new career opportunities that will enable us to make this field so much more attractive to potential scientists. The positive impact of such a program will be measured not only by the enhanced student enrollments, but also by the positive impact such a program has on the principal investigators themselves.

As welcome as this new program is, however, the need for additional training funds in the biomedical sciences is still tremendous. The lack of appropriate resources in these areas is seriously curtailing our ability to attract bright new students and is directly affecting our ability to carry out new research.

The second issue pertains to the need to enhance the pool of individual investigator-initiated awards. As you are well aware, revolutionary scientific discoveries seldom come in a predictable and orderly fashion. They are, in most cases, the result of ingenuity, creativity, luck and a good measure of hard work. Time and again, we read about the investigator who "stumbled" onto the magic ingredient for the cure of an ailment, or the researcher who, while working on one project opened up an exciting new field in a seemingly unrelated area. The examples abound: from penicillin to chemotherapy for testicular cancer, from the development of tissue culture methods (required for growth of viruses) to the accidental discovery by the 1986 Nobel laureates in Medicine, that snake venom is a potent source of nerve growth factors.

Indeed, I can attest to this first hand. As an NIH-supported postdoctoral fellow researching sodium metabolism in squid nerve, I unexpectedly discovered a critical link between sodium and calcium metabolism. I was not then working in the hypertension field, but pursuit of these exciting results eventually led me to the development of what is today the most widely quoted theory about how excess dietary salt causes high blood pressure. I did not set up to look for this link, nor did I expect these results; however, the ability and flexibility to continue the research in this direction proved to be of direct benefit to the biomedical community.

Mr. Chairman, supporting investigators to carry out independent and innovative research projects is critical if we are to maintain a world leadership position in the biomedical field. I, therefore, respectfully request that the FY89 NIH budget provide for 7,400 new and competing grants. This number of awards, the proposed number of training positions, the biomedical research support grants program, cooperative clinical research, minority biomedical research support and the NIH intramural program will require a substantial increase in the NIH FY89 budget. We join with the Ad Hoc Group for Medical Funding in recommending a FY89 appropriation of $8.2 billion (including AIDS funding).

Finally, Mr. Chairman, I would like to bring to your attention an issue which concerns us greatly: the "downward negotiations" on research grants. By NIH's own admission, budget cuts on new grants and competitive renewals are averaging 11% and over 7% for non-competing continuations. These cuts are severely eroding our research infrastructure and are creating havoc within our laboratories. Indeed, if the President's budget is honored, these cuts could be as high as 13% in FY89. These arbitrary, non-scientific cuts must be curtailed if biomedical research in our country is to continue.

Mr. Chairman, thank you again for this opportunity to share our views with you. The funds you will appropriate are part of the public trust and I firmly believe the public supports our efforts to enhance the quality of life through research. Thank you.

STATEMENT OF LOWELL PAUL HAGER, PROFESSOR AND DIRECTOR, BIOTECHNOLOGY CENTER, UNIVERSITY OF ILLINOIS

My name is Lowell Paul Hager, I am Professor and Head of Biochemistry and Director of the Biotechnology Center at the University of Illinois. For the past four years, I have also served on the Institute of General Medical Sciences Committee which reviews all training grant applications in the area of biochemistry, cell and molecular biology. This past year I served as Chairman of that Committee. On the basis of my teaching, research and administrative activities at a large public research university and in my role as a consultant to the single federal agency which provides most of the support for predoctoral training in the biological and medical sciences, I feel uniquely qualified to comment on the need for enhanced future funding for training in this area. In particular, I am convinced that it would be most unwise for the United States of America to fail to invest in the development of the future scientists which must provide the manpower and the brains which will keep the United States in the forefront of the new and highly competitive field we call biotechnology.

The late 1920s and early 1930s have often been referred to as the "Golden Age of Physics". During a relatively brief span of 10 years, amazing progress was made in the understanding of the physics and chemistry of the atom. For good or bad these scientific advances gave birth to the nuclear age.

I contend that the biological sciences are now in the midst of a "Golden Age" the equivalent of that in physics. In contrast to the relatively short 10 years for the burst of knowledge concerning the physical world, the biological "Golden Age" promises to extend over a much longer period of time. I think most would agree that the elucidation in 1954 of the structure of DNA marked the beginning biological sciences "Golden Age" and in the years since a continuing series of dramtic discoveries has revolutionized our understanding of the basic biological processes which promote and sustain life on this earth. Today, Biotechnologists routinely perform experiments in genetic engineering which add new genes or change old genes in microbial cells. These experiments were unthinkable 15 years ago.

The National Institute of General Medical Sciences currently supports 1800 trainees working in the biological and medical sciences toward their Ph.D. degree. These traineeships have provided a mechanism for developing a cadre of young biomedical researchers who will provide the foundation for the future fundamental and applied research carried out in industrial, government, and academic laboratories. The National Institute of General Medical Sciences traineeships undergirds all of the research programs in the other categorical National Health Institutes. Unfortunately, there has been a decline in the number of total students and institutions which are funded in these training programs. The total number of institutions involved in the NIGMS training program has dropped by 1/3 in comparison to the 1970's. Currently only 60 institutions in 29 states participate. The NIGMS traineeships are awarded on a merit basis to a group of highly qualified and gifted students; however, there remains a large pool of essentially equally qualified students who do not receive traineeships because of lack of funds. In addition, almost all Universities and institutions involved in the training program limit the tenure of their traineeships to a maximum of 3 years, yet the average residence time in training for the Ph.D. degree is now 5 years. All of the current training programs are funded well below their recommended levels. At best, the programs received only 75% of the recommended funds. Furthermore, graduate students in the biological and natural sciences are generally supported at a level of approximately $10,000 per year above and beyond tuition and fee expenses. This stipend level is considered to be at the bare subsistence level. The NIH training stipend is $6552 per year. Thus those institutions which are good enough and lucky enough to qualify for training support face the new problem of finding funds to supplement trainee stipends and provide for two additional years of support. In sum, I contend that not only do we not support sufficient numbers of students for our country's future needs in the biomedical and biotechnological field, but that the support dollars for the present trainees are totally inadequate.

It is estimated that investments in the biotechnology industries will exceed 20 billion over the next 20 years. Investments to date exceed 5 billion. This is an industry created and sustained by the scientists who trained only a few short years ago in the kind of programs I have been discussing. The growth of biotechnology in the United States and in the other major industrial countries has been exponential. This exponential growth should continue in the United States for the next 5 to 10 years if we expect the U.S. to maintain its current leadership role. I predict that we will surrender this leadership role to Japan in the 1990's if we now fail to act.

STATEMENT OF THE SOUTHERN CALIFORNIA GAS CO.

Chairman Childs and members of the Senate Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education and Related Agencies, my name is Michael Neiggemann. I am Vice President of Consumer Services for Southern California Gas Company. I appreciate this opportunity to express our strong support for adequate TY 1989 funding for the Low-Income Home Energy Assistance Program (LIHEAP) -- preferably at a dollar level near the $1.825 billion level appropriated in TY 1987 but at least at the $1.59 billion level recommended by the House and Senate Budget Committees.

Congress should be commended for fashioning LIHEAP and for authorizing adequate funding to make the program work. Unfortunately, however, recent concern for controlling federal spending has jeopardized continued LIHEAP funding at levels adequate to help the growing number of needy people nationwide.

Statistics published in the 1989 State of California budget illustrate how the need is growing while funds are diminishing in our state.

According to the California Department of Economic Opportunity, the agency that administers LIHEAP in our state, only about 670,000 of the state's 1.6 million low-income households received LIHEAP aid in 1986-87. About 490,000 received LIHEAP assistance; 133,000 received ECIP crisis assistance; and 47,000 benefited from the weatherization program. During the most recent winter, the

Department helped about 728,000 households. Next year it expects to serve about 776,000. That is a 16 percent increase in the number of families served in two years. Compare that to the 25 percent nationwide decrease in the amount of money available to help these families: from about $2 billion in TY 1986 to $1.5 billion this year.

Even assuming Congress follows the Senate and House Budget Committees' recommendations to appropriate $1.59 billion for LIHEAP, this modest 4.2 percent increase will not keep pace with the growing number of people needing help. More people, less money -- either the number of people being helped will be cut back, or individual payments will be reduced.

Already, agencies that distribute these funds have told us they have reduced the maximum amount of assistance they will give. So, in many instances, low-income people are eligible to receive $300 but they only are given $150.

Even with this effort to stretch the funds, the agencies tell us that people are competing with each other for what little assistance is available. Agency workers tell us they feel like Solomon, forced to make difficult choices of who will get help and who won't.

Obviously, reducing LIHEAP funding would have devastating effects on needy people. So, the Administration's proposal to fund LIHEAP at $1.2 billion is unthinkable. Preferably, Congress should provide funding nearer the $1.825 billion level appropriated in TY 1987, as proposed by a group of concerned members of the House of Representatives.

Our Company is the largest gas distribution utility in the nation. We serve about 4.2 million customers, nearly 3.4 million of which are families. Of this total, about 800,000 households (or 20 percent) are classified as low income. This poverty is especially pervasive among customers in our minority communities. In Los Angeles, for example, 28 percent of low-income families are Black. About 42 percent are Hispanic.

In light of this significant number of low-income families in our service area, our Company has been a long time advocate of programs to help needy people deal with the rising costs of living. We have been an especially active supporter of LIHEAP since its inception late in the Carter Administration. Our chairman, Robert M. McIntyre, has personally expressed this support in letters, telegrams and personal conversations with members of Congress and the Administration. We were instrumental in forming a broad-based community coalition in mid-1985 that sought to maintain adequate federal funding of the LIHEAP programs and to urge the State of California to streamline its process for administering those funds. Our Company has also been a leader in developing innovative utility programs to help low-income people: consumer information programs, bill payment plans, a fuel fund, and a special low-income weatherization program that has earned accolades from the California State government, consumer groups, and the White House.

We feel LIHEAP is an important element for helping low-income people. It sets the tone -- a precedent -- for other public and private sector efforts supporting the needy. It is a safety net that enables needy families like those with a single mother or a wage-earner who is temporarily unemployed meet unexpected financial emergencies that threaten their ability to keep their homes warm during the winter. More important, we feel it provides a mechanism for helping these people get out of the cycle that led them to need assistance in the first place: applicants are directed to weatherization programs that enable them to reduce energy use and hence keep utility bills lower.

Before concluding, I would like to take a moment to rebut those who argue that oil overcharge revenues from the Petroleum Violation Escrow Account (PVEA) could augment declining LIHEAP funding. The Administration and its supporters for a number of years have been proposing this funding mechanism in lieu of LIHEAP funds from the General Fund. In California, this approach has not worked.

Ever since oil overcharge money first became available here, only a small portion of those funds has gone to help low-income consumers. Most has been diverted to California Energy Commission research and demonstration programs. The same holds for plans to use these funds next year. According to the State budget, California expects about $147 million in overcharge funds. Of this total, only $10 million has been planned for energy assistance. Again, the lion's share will go to Energy Commission programs-- $100 million of which will be used for a school bus demonstration project. Making a budget decision in Washington to reduce LIHEAP funding, with the expectation that PVEA funds will be used to make up a funding shortfall, ignores our experience that, in California, this money will go elsewhere. Worse, there are no assurances PVEA funds will continue to be available. So, reducing LIHEAP funding now with the promise of PVEA support sets a budget precedent from which it will be difficult to recover in future years.

In closing, I would like to commend the subcommittee for giving such close scrutiny to the merits of funding LIHEAP. We encourage you to approve an appropriation near the $1.825 billion funding level of TY 1987. At the minimum, we support funding at the $1.59 billion level recommended by the Budget committees. We strongly urge you to resist pressures from the Administration to slash LIHEAP funding to $1.2 billion and in so doing seal the demise of what has been a valuable and viable system for helping low-income people meet their home energy needs.

STATEMENT OF PARENTS ANONYMOUS

According to a recent HHS request for proposals in the Federal Register, "the number of reports of suspected child abuse and neglect received by Child Protective Service (CPS) agencies has escalated at a rate often beyond the agencies' capacity to respond fully to each report." Furthermore, even after investigation by CPS these reports are often officially unsubstantiated, even though there may be strong reason to suspect that abuse has occurred. The CPS system is staggering under the weight of the load which society has placed upon it, and, in fact, has never fully recovered from the cuts it sustained in the early 1980's.

Concomitantly, interest in the issue of child abuse has increased. Today the general public is far more aware of the problem than ever before, and the number of child abuse reports continue to increase in every state.

Parents Anonymous is a national network of approximately 1500 state and community based programs designed to provide families with accessible help in reducing the frequency and intensity of child abuse episodes within the family. This network includes state and regional organizations which are responsible for developing programs for parents and children at the local level. All services to families are offered free of charge.

The effectiveness of the Parents Anonymous model of intervention has been evaluated in a comparison study of 11 child abuse programs. This evaluation found that Parents Anonymous was the most effective way of dealing with parental abuse, regardless of what other form of treatment was offered.

Parents Anonymous offers services to two populations - parents who voluntarily seek our services because they recognize they are being abusive, or fear they may be, and parents who have been referred by CPS or the Courts.

The grass roots approach utilized by Parents Anonymous makes it both cost effective and attractive to those in need of the service. Many parents, who because of their fear and distrust of mental health professionals would never voluntarily seek help, find the low key atmosphere of the Parents Anonymous parent support group a comfortable environment. Because Parents Anonymous groups do not exist within an agency structure, they do not require the financial support for administrative overhead and salaries. And, the professionals who facilitate the parent groups volunteer their time.

The program does require some administrative support however, if the parent groups and children's programs are to survive. The state and regional offices provide that support, and are responsible for raising their own funds within a given state.

The national office delivers support services to the states by serving as a data collection point, developing training models and materials, providing leadership in new program directions and overseeing the implementation of national policies and guidelines. This existing network of administrative offices and direct service programs comprises the largest service delivery system, apart from the CPS system, in the nation.

Parents Anonymous' goal is to have in place a collaborative relationship between itself and CPS in order to more effectively serve families which have been reported for abuse. The earmark would be utilized in the following manner:

- Development of a model for collaboration between Parents Anonymous and CPS; and
- Development of training modules and supporting materials.

The mechanism for providing a primary intervention resource to Child Protective Services in order that it may comply with the provisions of the Family Reunification and Adoption Act is already in existence - Parents Anonymous.

STATEMENT OF THE ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

CENTERS FOR DISEASE CONTROL

The state health departments have been active partners with the CDC in disease prevention, lending support to and being supported by the programs of CDC. While our successes have been many, we still have much to do to prevent and control the diseases that are afflicting so many in our population. Although the President's budget has maintained or modestly increased some important health programs, its overall vision for this nation's public health needs falls short of reasonable expectations.

The Preventive Health and Health Services Block Grant is the backbone of public health and the only source of funding for prevention activities with which States can address the special needs of its citizens. The Prevention Block Grant provides the flexibility needed to target specific populations, and to create new and innovative programs that can affect health outcomes.

Federal funds account for approximately one-third of state and local health department expenditures, but federal support through the Preventive Health and Health Services programs accounts for slightly more than 1 percent of these expenditures. State and local resources for disease prevention and control far outstrip federal support for many program areas, for example, tuberculosis control, epidemiology, chronic disease, cancer control, and renal disease. However, the Prevention Block Grant represents a significant source of funds for particular programs, for example, rape prevention, hypertension control, health education and risk reduction, and rodent control.

It is crucial that federal funding for the Prevention Block Grant be increased beyond 1 percent of state public health expenditures in order that prevention activities be expanded, so that states may undertake additional public health intervention techniques, and so that unmet needs among target populations can be addressed. ASTHO recommends an appropriation of $128.5 million for the Prevention Health and Health Services Block Grant.

The Immunization Program is among the most cost-effective and cost-saving health measures available today. However, the spiraling costs of vaccines and their ability to provide the necessary immunizations to the children in their state are a major concern of state health departments. Complicating the issue of vaccine costs is the increase in referrals from the private to the public sector reported by many states. These referrals will place an additional and substantial burden on health department immunization budgets.

The rise in vaccine costs and the need to provide an adequate supply of Haemophilus Influenza B vaccine, the cause of bacterial meningitis, to public health departments speak to a significant funding increase for the immunization program. ASTHO recommends an appropriation of $117 million for grants to states, which includes the cost of vaccines and the additional administrative expenses of the new vaccine program, $18 million for program operations, $5 million to maintain an adequate stockpile of vaccines, and $12 million for the HIB vaccines.

Sexually transmitted disease continues to plague this nation, exceeding $3 billion annually in cost. Further, the cost of pelvic inflammatory disease and associated ectopic pregnancy and infertility exceeded $2.6 billion in 1985. CDC estimates that sexually transmitted diseases which threaten primarily adolescents and young adults have increased to almost 14 million cases per year including:

- 1.8 million cases of gonorrhea;
- 85,000 cases of syphilis;
- 4.0 million cases of chlamyhdia;
- 1.0 million cases of human papilloma virus;
- 200,000 to 500,000 cases of genital herpes;
- 3.0 million cases of trichomoniasis;
- 1.2 million cases of urethutis; and
- 1.0 million cases of mucopurulent cervicitis.

In recent years attention has focused on the incidence of chlamyhdia, which has been identified as more prevalent than gonorrhea in our population. Indeed, there is a great need for more screening and follow-up for chlamydia, as well as for the implementation of chlamydia control guidelines.

Also, in 1987 we saw a 30 percent increase in syphilis from the previous year, the single largest increase in 30 years. In some areas of the country, for example New York City and some areas of California and Florida, the increase over last year was as great as 100 percent.

In order to make progress toward reducing the incidence of these sexually transmitted diseases, and step up efforts toward control of chlamydia and syphilis, additional resources are urgently needed. The Administration has proposed no increase in funds for STDs, which would severely hinder important efforts toward prevention and control of these diseases. ASTHO recommends that Congress appropriate $110 million for the nation's sexually transmitted disease program.

The Tuberculosis program has been slated for only a slight increase in the President's budget. ASTHO believes that funding for this program must be increased dramatically. Despite the great decline in morbidity and mortality we have seen over the past four decades, TB continues to be a significant public health problem. Of the 22,255 cases reported in 1984, 1,236 cases were in children under 15 years of age and 759 in children under 5 years of age. The occurrence of TB in children is of particular public health significance because it indicates that transmission of tuberculosis is occurring in the community.

Tuberculosis takes its greatest toll on older age groups, minorities and the socio-economically disadvantaged. While 30.8 percent of the total population is 45 years or older, 58.1 percent of the cases of TB in the U.S. occur in persons 45 years or older. The case rate for persons 65 years and over is 23.2 per 100,000 compared to 8.4 per 100,000 for persons 25-34. Furthermore, cases of TB in non-whites comprised 47.3 percent of the U.S. morbidity, while non-whites made up only 15 percent of the population. The case rate is consistently higher for non-whites--29.9 per 100,000 compared to 5.8 per 100,000.

In terms of geographic distribution, the portion of the population residing in cities of less than 100,000 and in non-urban areas contributed 54 percent of all reported cases. In other words, TB cases are occurring sporadically in areas where clinical expertise on the diagnosis and treatment of the disease is disappearing.

Another more serious problem is reflected in the fact that the highest rates occur in major cities where, not coincidently, the highest AIDS rates occur. For the past several years, numerous reports have indicated that mycobacterial infections are common among AIDS patients. The primary fear here is that this will increase the risk of TB infection for the general public and particularly health care workers and family members, including children, and others living with and caring for people with AIDS.

The Tuberculosis Control Program is facing new challenges and support for its activities must increase rather than decline. Therefore, ASTHO recommends an appropriation of $15 million for the TB Program.

Over the last few years this country has experienced a major new public health problem, Acquired Immune Deficiency Syndrome. Both the public and private sectors have recognized the urgency of this disease and the need for increased resources and expanded research, education and surveillance activities. There is no debate that health education and risk reduction activities for prevention are the only defenses available to combat AIDS and HIV infection. State and local health agencies are on the frontline of this battle and are acutely aware of the funding needed to make an impact on this disease. ASTHO supports an appropriation of $1.3 billion for AIDS research, treatment, care and recommends an additional $700 million for education and information, including counseling and testing.

Injury, as the fourth leading cause of death in the U.S., constitutes a major public health problem. Every year there are 140,000 deaths due to unintentional (accidental) and intentional (self-inflicted and violent) causes. Among children and young adults, injuries are the leading cause of death, surpassing all other diseases. Injuries can be diminished considerably if adequate attention and support are allocated to proven strategies. Federal support through funding for injury research and application of results is critical to achieving desired goals of injury prevention. ASTHO recommends an increase in appropriations for injury prevention to $10 million.

MATERNAL AND CHILD HEALTH

ASTHO would also like to voice its support for the activities provided through the Maternal and Child Health Block Grant. This Block Grant enables States to provide essential services to improve the health of the women and children at risk in their communities. The President's budget asks for $56 million for the MCH Block Grant. ASTHO concurs with this ceiling amount to allow states to meet the increasing need for services and also to provide states with the option to develop child health projects to serve children who are medically underserved because of special health care needs, geographic isolation, or unusual medical or social risks.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION

Finally, ASTHO recommends a $1/2 million increase to $3.5 million for the Office of Disease Prevention and Health Promotion so that we can better ascertain our nation's health and medical care requirements and objectives.

Summary of ASTHO Recommendations

Program	1988 Appropriation ($ million)	President's Budget ($ million)	ASTHO Recommendation ($ million)
Prevention Block Grant	85.7	85.0	128.5
Sexually Transmitted Disease	65.2	65.5	110.0
Immunization			
- Grants	86.0	93.0	117.0
*- Operations	8.0	8.0	24.0
- Stockpile	3.8	.0	5.0
- HIB	.0	.0	12.0
TB Control	6.7	7.0	15.0
AIDS			
- Research			1,000.0
- Care	591.0	900.0	300.0
- Prevention/ Education	315.0	400.0	700.0
MCH Block Grant	526.0	561.0	561.0
Injury Prevention	1.4	1.4	10.0
Office of Disease Prevention and Health Promotion	3.5	3.0	3.5

* ASTHO's funding request for FY'89 State operations includes $6 million for the printing and distribution of informed consent forms, as specified in the National Childhood Vaccine Injury Act.

STATEMENT OF THE NATIONAL DIGESTIVE DISEASES ADVISORY BOARD

I am Dr. Francis J. Tedesco, Interim Dean, Vice President for Clinical Activities, Medical College of Georgia in Augusta, Georgia, and Chairman of the National Digestive Diseases Advisory Board (NDDAB).

Recognition of the serious impact of digestive diseases led Congress to establish the National Commission on Digestive Diseases in 1976 to prepare a national long-range plan for reducing the social and economic burden of these diseases. The NDDAB was established in 1980 to monitor the implementation of the national plan and periodically update it. I am pleased to have the opportunity to present the Board's recommendations.

The wide spectrum of disorders known collectively as digestive diseases are grouped together because they all affect the gastrointestinal system, which includes the esophagus, stomach, small and large intestines, anorectum, liver, biliary tract, and pancreas. Numerous acute and chronic digestive diseases afflict Americans, ranging from serious and sometimes life-threatening illnesses such as hepatitis, cirrhosis of the liver, Crohn's disease, cystic fibrosis, and cancer to more common conditions such as gallstones, diarrhea, and hemorrhoids. More Americans are hospitalized for digestive diseases than for any other types of illnesses, accounting for almost 15 percent of all admissions to general hospitals and for 25 percent of all surgical procedures.

More than one-half of the U.S. population are affected by a digestive disorder at some time during their lives, costing the Nation $50 billion annually. Digestive diseases cause approximately 200,000 deaths yearly.

Digestive diseases are the leading cause of loss of time from work for male employees, and impair more than 2 million Americans. Approximately 140,000 veterans receive payments for service-related disabilities due to gastrointestinal disorders.

Despite these bleak statistics, biomedical research has helped to expand our understanding of some of the causes of these diseases as well as ways to prevent and treat them. Our latest annual report, which will be made available to the committee today, provides highlights of such research. Also in the report are several priority recommendations I will briefly summarize today.

NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK)

The NIDDK is the lead agency for biomedical research and training related to digestive diseases. Support of research and related training and education programs directed to reducing the impact of digestive diseases is a cost-effective investment that will yield considerable return in the coming years. To permit digestive diseases programs to grow at the rate recommended by the Commission, funding for the entire NIDDK must be increased.

THE BOARD RECOMMENDS THAT THE TOTAL NIDDK BUDGET BE INCREASED TO $680 MILLION IN FISCAL YEAR 1989 TO SUPPORT THE PROGRAMS THAT I WILL NOW DESCRIBE.

RESEARCH CENTERS

NIDDK supports 12 Digestive Diseases Research Centers that provide shared (core) research facilities and resources that expand and improve the effectiveness of digestive diseases research and facilitate collaboration among many investigators. The centers also provide an effective setting for training young scientists in the methods and understanding of basic and clinical research. The NIDDK also supports six Clinical Nutrition Research Units, which conduct research in nutrition areas closely related to digestive diseases.

The budget for these centers has been significantly reduced in the past 2 years because of general budgetary constraints experienced by the NIDDK. These reductions seriously restrict current research programs, interfere with long-term planning and recruitment, and undermine the ability of the centers to accomplish the tasks for which they were originally approved and funded.

THE BOARD RECOMMENDS THAT $15 MILLION BE MADE AVAILABLE TO THE NIDDK IN FISCAL YEAR 1989 TO SUPPORT THE 12 DIGESTIVE DISEASES RESEARCH CENTERS AND THE 6 CLINICAL NUTRITION RESEARCH UNITS AT RECOMMENDED BUDGET LEVELS.

INDIVIDUAL RESEARCH GRANTS

The percentage of approved individual research grants funded by NIDDK has declined from about 45 percent a few years ago to just 25 percent in recent years. As a result, outstanding research programs are terminated prematurely, and promising new investigators are unable to obtain support for their projects.

THE BOARD STRONGLY RECOMMENDS THAT THE NIDDK RECEIVE SUFFICIENT RESOURCES TO FUND 45 PERCENT OF COMPETING RESEARCH GRANTS AT BUDGET LEVELS RECOMMENDED BY THE SCIENTIFIC REVIEW COMMITTEES.

RESEARCH TRAINING AND CAREER DEVELOPMENT

It is critical that new investigators be trained for research careers and that current investigators be prepared to apply the modern research advances and techniques of basic science to the complex problems of digestive diseases. Bright young scientists have become discouraged both by the reduction in the percentage of approved research applications that can be supported within current funding levels and by the limited number of training and development awards.

THE BOARD RECOMMENDS THAT $8.5 MILLION BE MADE AVAILABLE TO THE NIDDK IN FISCAL YEAR 1989 FOR TRAINING AND CAREER DEVELOPMENT AWARDS IN DIGESTIVE DISEASES.

Epidemiologic studies to compile data on the scope and impact of digestive diseases and the outcome of interventions are critical to planning for the control of digestive diseases. Such studies have been hindered by the inadequate number of professionals trained in epidemiology and related disciplines.

THE BOARD RECOMMENDS THAT THE NIDDK RECEIVE AN ADDITIONAL $350,000 TO SUPPORT FIVE RESEARCH CAREER DEVELOPMENT AWARDS IN THE FIELD OF EPIDEMIOLOGY AND DIGESTIVE DISEASES.

NUTRITION ACADEMIC AWARDS

Nutrition is a key factor in many digestive diseases. Significant advances in nutrition research have occurred that should be incorporated into medical teaching programs to facilitate transferring this knowledge from the laboratory to the patient. Therefore, the Board recommends that Nutrition Academic Awards be established to: (1) provide a stimulus for developing nutrition curriculums in schools that lack such programs and (2) strengthen and improve existing nutrition curriculums.

THE BOARD RECOMMENDS THAT THE NIDDK RECEIVE AN ADDITIONAL $375,000 TO FUND FIVE NUTRITION ACADEMIC AWARDS ANNUALLY. THESE FUNDS SHOULD BE IN ADDITION TO THE NIDDK'S EXISTING BUDGET FOR RESEARCH TRAINING AND CAREER DEVELOPMENT AWARDS.

NATIONAL DIGESTIVE DISEASES DATA SYSTEM

The National Digestive Diseases Data System was established to collect, analyze, and disseminate data on the prevalence and impact of digestive diseases to guide research and health care delivery policy. When fully implemented, this resource will be invaluable in assessing the scope of digestive diseases, determining health care delivery policy, and identifying areas for future research. However, many vital components of the system cannot be implemented within the current budget level.

THE BOARD RECOMMENDS THAT $4.5 MILLION BE PROVIDED TO THE NIDDK FOR THE NATIONAL DIGESTIVE DISEASES DATA SYSTEM.

AIDS RESEARCH

Research involving the gastrointestinal tract is highly relevant to the study of acquired immune deficiency syndrome (AIDS). Currently, several digestive diseases research activities offer the potential for discovery of new ways to treat AIDS. Given the importance of such research, the Board believes that funding for AIDS research activities should be increased.

THE BOARD RECOMMENDS THAT AT LEAST $3.5 MILLION BE MADE AVAILABLE TO THE NIDDK FOR DIGESTIVE DISEASES RESEARCH RELATED TO AIDS.

Thank you for the privilege of appearing before your subcommittee. I will be pleased to respond to any questions you may have.

STATEMENT OF THE PAGET'S DISEASE FOUNDATION

The Paget's Disease Foundation supports the funding requested by the National Institute of Arthritis and Musculoskeletal and Skin Diseases for the fiscal year 1989. The $224 million requested is needed by the NIAMS to maintain its vital work.

Paget's disease of bone is the nation's number two bone disease, after osteoporosis. It is present most frequently in a mild form, and is often misdiagnosed as arthritis. However, when Paget's disease progresses it can cause devasting pain and crippling.

Because Paget's disease affects mainly senior citizens, these patients also must endure many of the other sicknesses and disabilities of the elderly as well as the economic problems which the elderly must deal with. Because the drug therapies used to treat Paget's disease are very expensive, the cost of properly managing the disease is often an impossibility for the patient.

Excerpts from a recent letter dramatically tell of the hardships Paget's patients suffer.

"I found out that I had Paget's disease in 1978 when I was in the hospital with a broken leg. I lost my left leg due to a fire when I was six years old. I am now 68 years old and confined to a wheelchair.

The first drug that my doctor prescribed was Diodronel and it did help me to some degree. He turned me over to another doctor who put me on Calcitonin which I had to inject into my leg every day. It made me so sick and dizzy that I had to stop taking it. I was doing OK until a couple of months ago when I began having pain in my knee and my leg became very stiff and sore. I went to arthritis specialist and he put me back on Didronel. He does not know a great deal about Paget's disease and he questions the length of time that I should take Didronel. Can you please tell me how long it is safe to stay on Didronel before stopping it and are there any other drugs I can take without such bad side effects as Calcitonin. I know that my age may be against me and my right wrist is badly bowed and my leg is also bowed.

My head has increased from a size 7 to size 8 and it is hard to find a hat that fits my head. From all of this you can add that I am in trouble and need help. I study medical books, call doctors on talk shows and have written to medical schools and universities. I am a poor man and do not have very much money, but I am sending you a contribution and pray you will send me all the information you can about the drugs, treatment and general information on Paget's. Thank you very much and good luck."

Paget's disease has been recognized since 1878, but there had been no cure or help for it until recently. Through research, some underwritten by the National Institutes of Health, several drug therapies have been developed which appear to slow down the progress of the disease and alleviate its symptoms.

These drug therapies, however, are far from a panacea. As physicians have worked with them during the past ten years, they have found that numerous patients do not respond to them satisfactorily. Physicians are loking now to more effective forms of the drugs to be developed. At the same time, they are seeking to learn the cause of the disease, and to better understand the patient population which the disease affects.

There are very few researchers working on Paget's disease today, largely, we feel, because the resources for funding grants appear to be highly limited. Also, because the disease has a low profile in both the public sector and the scientific community, major research focus has been concentrated elsewhere. The Poaget's Disease Foundation is working hard to improve the Paget's research situation, mainly through the National Institute of Arthritis and Musculoskeletal and Skin Disorders and also with the support of the private sector.

The Paget's Disease Foundation was formed 10 years ago to help patients and physicians learn about the disease and its new therapies. Because the disease has been so often misdiagnosed or dismissed by physicians, we estimate that only about 200,000 patients are under treatment for their disease.

The Foundation has mounted and will continue to aggressively mount on-going public awareness campaigns to reach more patients who need help. Also, we are greatly expanding our efforts to reach and work with the medical practitioners who treat these patients.

The support of Congress is necessary in order for the NIAMS and the Paget's Disease Foundation to better assist sufferers of this painful and debilitating disease.

STATEMENT OF THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Mr. Chairman, I am Karen Antman, M.D., testifying today on behalf of the American Society of Clinical Oncology (ASCO).

I am an Associate Professor at the Dana-Farber Cancer Institute and Harvard Medical School in Boston, Massachusetts and, as a volunteer, I chair the Public Issues Committee of ASCO.

The American Society of Clinical Oncology, founded 20 years ago, is the largest organization of physicians and scientists specializing in cancer, including prevention, treatment, teaching and research. Its members include the nation's leading physicians in medical and pediatric oncology, radiation therapy, surgical and gynecologic oncology, and also basic scientists in pathology, immunology, pharmacology, biostatistics, and other basic biomedical sciences, in literally all of the nation's medical schools, cancer hospitals, centers and institutes.

Thank you for your support in the past and particularly last year.

First, Mr. Chairman, ASCO would like to thank you and your committee for your continued strong support for both the National Cancer Institute and the National Institutes of Health. Your support is particularly welcome in this era of budgetary restraint and we are deeply grateful.

We support the following appropriations levels.

ASCO supports for the National Cancer Institute (NCI) a funding level of $2.1 billion for fiscal year 1989. This level called for in the "By-Pass Budget" of the NCI has been arrived at by experts in public policy in the field of cancer research, and supported by the National Coalition for Cancer Research.

Additionally, Mr. Chairman, there is a dire need for funding for construction grants and for equipment. Biomedical research requires sufficient space and up-to-date equipment.

We support the Ad Hoc Coalition on Medical Research in their request for $8.2 billion overall for the National Institutes of Health.

Expression of Concerns

We are very concerned about two patterns of funding for NCI programs.

The first is inadequate funding of cancer centers. Funding for cancer centers has increased by only about 4% per year. That is approximately 19% over the last five years. This is in comparison to an increase in funding of the NCI of 45% and the NIH of 50%. Core grants make R01 grants more efficient by allowing the purchase of large required shared equipment and the maintenance of personnel to permit collaborative research.

The second is funding for clinical research, especially patient care in clinical trials.

Opportunities for clinical research today far exceed the money currently available.

In addition, although the NCI in the past provided financial support for the care of patients on selected clinical research trials through program project or clinical center grants, for about the last decade funding for patient care costs has been deleted from research grant budgets. Recently, many third party payers have refused to support the patient care component of research trials for cancer.

The current budgetary constraints imposed on Federal support for biomedical research make it unlikely that research grants will be able to fill this gap in the future. This impasse threatens to seriously compromise clinical investigations that would lead to progress in the treatment of cancer.

Identification of a new effective therapy requires an orderly progression of several trials.

The objective of clinical (treatment) research is the development of improved cancer therapy. There is an orderly progression from basic laboratory science to exploratory (phase I & II) studies, and then to large phase III trials definitely testing a new treatment strategy. These phase III trials generally randomize patients to receive either the new treatment or the best standard therapy. Because they are complex in design, and involve hundreds of patients, they are expensive and frequently take 3-4 years. NCI supports clinical treatment research primarily through research contracts for early clinical phases of new drug development, and via cooperative agreements with the Clinical Cooperative Groups.

The patients eligible for the treatment trials in question include the majority of individuals with advanced cancer, for whom no known cure is available. When informed of the gravity of their clinical problem, many such patients ask for, and even insist upon trying an investigational therapy. The majority will refuse a 'no therapy' recommendation, even if their physician indicates that this is a reasonable and humane course of action.

Many health insurance companies have recently adopted the position of refusing to cover investigational therapy, defined as treatment with any non-FDA approved drug, or utilizing approved drugs in non-approved doses or schedules. Health care insurers currently are under great financial pressure, and are understandably committed to reducing the costs of health care. This problem is obviously not unique to cancer therapy. Examples in other disciplines include third party payors' unwillingness to cover admissions for investigational agents in patients who have failed all standard therapy for refractory arrythmias. An analysis of the issues in cancer therapy, however, should serve as a model with applications in other medical disciplines as well.

How should the costs of clinical research be borne? One approach would have patients themselves cover these costs. This would create a policy guaranteeing that new, experimental therapies would be available only to the affluent members of society.

A second approach is the reinstitution of patient care costs into research grants. Currently research grant budgets generally cover the costs of collecting data, sending slides for histologic review, and laboratory tests not otherwise required for patient care. If hospital admission is required for the treatment research an almost ten-fold increase in the grant budget would be necessary. Grant funding of hospitalization costs, furthermore, would be enormously difficult to monitor and/or to justify. Patients with advanced metastatic cancer require hospitalization for a variety of complications which are often coincident with, but unrelated to, administration of investigational therapy. These costs are properly assumed by their insurance coverage.

Current budgetary constraints imposed on Federal support for biomedical research almost certainly preclude grant support of patient care costs for investigational therapies. On the other hand, we believe Congress should require that Medicare cover participation in clinical trials. Since the government is also one of the largest employers, Congress should also insist that government employees be covered for participation in clinical trials, funded through either Medicare, or the third party carriers.

Historically, hospital expenses of patients participating in Phase I and II studies have been paid by third-party insurers. In the absence of a research trial such patients would be treated with standard therapies despite lack of substantial benefit. Marginal treatments are routinely compensated by third parties.

Since standard therapy is known to be of limited effectiveness, scientifically and ethically sound trials of investigative treatments are justified, and at the least, provide an element of greater hope for the patient and family. In this clinical setting, investigational treatment should be equated with "state of the art" care. One can argue that participation in therapeutic trials by patients with advanced, incurable cancers, assuming that the clinical studies are scientifically and ethically sound, is the best available form of medical care for the group of patients who decide on active therapy, and thus should be covered. Continued third-party payment is therefore appropriate.

Whether funded by tax dollars or via medical insurance, the costs of this type of care are ultimately borne by the health care consumer who ultimately benefits by any achievements in the clinical trial.

While investigational treatment may increase costs in the short run, where they evolve into curative therapy, the costs of an illness to society will be decreased. An example is the cure of advanced lymphoma or testis cancer with a series of two to six monthly courses of chemotherapy. In the long run, clinical investigation is cost effective.

Thank you for considering my views. I will be pleased to answer any questions you may have.

STATEMENT OF THE COUNCIL OF GRADUATE DEPARTMENTS OF PSYCHOLOGY

Mr. Chairman and Members of the Subcommittee, I am Dr. Irwin L. Goldstein, Professor of Psychology and Chairman of the Department of Psychology at the University of Maryland in College Park, Maryland. I am pleased to testify as Secretary-Treasurer of the Council of Graduate Departments of Psychology (COGDOP). COGDOP represents over 300 graduate departments of psychology at colleges and universities around the country, including all of the major research universities and many medical centers and schools of education located in every state. My statement also represents the views of the American Psychological Association (APA). My testimony addresses fiscal year 1989 appropriations for the National Institutes of Health (NIH).

COGDOP and APA strongly believe that federal support for NIH must be maintained and expanded, and recommend $8.4 billion (including AIDS) in FY 1989 funding. Our proposal for $8.4 billion in FY 1989 funding for the National Institutes of Health was developed by the Ad Hoc Group for Medical Research Funding after careful consultation with NIH, and is grounded in sound scientific judgement. We greatly appreciate this Subcommittee's past support of the research conducted by NIH, and urge your continued investment in the NIH research budget.

COGDOP and APA recommend that the NIH establish each year meaningful and explicit goals to raise its expenditures on health and behavioral research above its current proportion of three percent to a target level of 10 percent. We believe that a tremendous opportunity for the Federal system of sponsored research rests with bringing into alignment support for biobehavioral research with the human and economic costs of behavior-related illness and disability to society.

Over the past ten years, there has been a growing recognition in the scientific community and among the public of the critical role of health and behavior in the diagnosis, treatment, and prevention of disease. The Institute of Medicine (IOM) in its 1982 report, Health and Behavior, said, "The burden of illness has shifted from acute infectious diseases to chronic diseases with multiple interacting risk factors, which prominently include such behavioral elements as smoking, alcohol, exercise, diet, and response to stress."

In response to the evidence that developments in many fields of biobehavioral sciences have great potential for improving the diagnosis, prevention, and treatment of illness, for the past four years this Subcommittee has directed NIH to increase its support for health and behavior research and to report back to Congress on its progress in this regard. On behalf of COGDOP and APA, I would like to commend you, Mr. Chairman, and the Subcommittee for your continued support for NIH-funded research on the role of behavioral and social influences on health promotion and disease prevention.

Unfortunately, however, the allocation of resources for research on health and behavior at NIH is not in keeping with what we have learned about the relationship of behavior to illness and disability in our society and to the associated cost of behaviorally influenced health problems. In recent years, the proportion of the overall NIH budget devoted to health and behavior research and research training has remained fairly constant at about three percent. In this year's report to Congress for fiscal year 1987, NIH reported that of its $6.2 billion budget, only $179 million, or 2.89 percent, was directed toward health and behavior research and research training.

As the nation's largest source of funding for biomedical and biobehavioral research, it is the role of NIH to foster basic inquiry in the area of health and behavior and its application to problems of health. The importance of this key role cannot be overstated. The support of NIH is essential to clarifying behavioral aspects of major health problems, such as heart disease and cancer, and to discovering approaches to preventing and managing these health-jeopardizing behaviors. Increasing the number of basic biobehavioral research awards, explicit acknowledgement of biobehavioral factors of disease in a substantial number of major research awards, and fostering interdisciplinary research between the biomedical and biobehavioral sciences would be significant steps toward achieving these goals.

COGDOP and APA further recommend a substantial increase in the number of NIH-supported research trainees. The IOM report, Health and Behavior, specifically called for increased federal support in behavioral research training. We urge the Subcommittee to provide research training funds sufficient to enable NIH to specifically enhance research and research training opportunities for behavioral scientists. We also urge your continued support for the Biomedical Research Support Grant Program and other mechanisms to further the support of new investigators, innovative research projects and techniques, and multi-disciplinary research.

COGDOP and APA strongly urge the continued support of the National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA), and recommend funding levels of $568.4 million and $281 million (including AIDS), respectively. NICHD is the major source of federal funding for research pertaining to maternal and child health and population sciences, and NIA is the primary federal agency with the mission of improving the quality of life of Americans as they age. These two Institutes conduct and fund valuable behavioral and social research, and our recommended levels of support will allow them to keep pace with the growth in new research opportunities in their respective areas.

COGDOP and APA recommend continued support for the National Cancer Institute (NCI), and urge the Committee to direct NCI to dedicate a larger proportion of its budget to behavioral research, particularly in the area of cancer prevention. NCI indicated in its component of the NIH report to the Committee on Appropriations, "Health and Behavior Research Initiatives by NIH, FY 1987" that smoking and tobacco use, diet and nutrition, and regular cancer screening, all behavioral factors, are critical to cancer control. In that report NCI said that 35 percent or more of cancer deaths may be related to diet and nutrition. Dr. DeVita, Director of the National Cancer Institute, told the House Subcommittee on Labor-Health and Human Services-Education Appropriations in his testimony on March 10, 1988 that if women over 50 were screened for breast cancer with mammography that breast cancer mortality would be reduced by 30 percent. He also told that Subcommittee that our national cancer rate is actually rising, despite biomedical research advances, due to epidemic lung cancer linked to smoking. Clearly, increased attention to biobehavioral research and human behavior is an important step in order for NCI to meet its goal of reducing our Nation's annual cancer death rate by 50 percent by the year 2000.

COGDOP and APA recommend that NHLBI's research budget be funded at $1.3 billion in FY 1989 (including AIDS), and that NHLBI be directed to significantly increase its percentage of funds dedicated to behavioral research. Fifty-five percent of all deaths in 1986 are accounted for by cardiovascular, lung, and blood diseases. These diseases represent five of the 10 leading causes of death, and are alone responsible for 24 percent of the total economic costs of all illnesses and premature deaths. No where is the relationship between health and behavior more clear than in coronary, lung, and blood diseases. Foremost among their risk factors are smoking, alcohol, exercise, diet, and response to stress -- all behavioral elements. Yet, even at NHLBI, behavioral research represents only three percent of the Institute's research effort. COGDOP and APA urge the Subcommittee to direct NHLBI to dedicate a greater proportion of research funds to studies of human behavior that provide the critical link between advances accomplished in the biomedical laboratory and actual improvement in human health.

Thank you for this opportunity to present the views of the Council of Graduate Departments of Psychology, and the American Psychological Association, on these important appropriations issues.

STATEMENT OF THE NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

THANK YOU FOR THE OPPORTUNITY TO APPEAR BEFORE YOU TO ADDRESS THE PRESIDENT'S FISCAL YEAR 1989 BUDGET REQUEST FOR FEDERAL ALCOHOL AND DRUG ABUSE PROGRAMS.

MY NAME IS ROBERT AUKERMAN. I AM DIRECTOR OF THE COLORADO STATE ALCOHOL AND DRUG ABUSE DIVISION AND AM APPEARING BEFORE YOU TODAY AS THE SECRETARY AND LEGISLATIVE COMMITTEE CHAIRMAN OF THE NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS (NASADAD). NASADAD IS A NOT-FOR-PROFIT ORGANIZATION WHOSE MEMBERSHIP IS EXCLUSIVELY COMPRISED OF THE STATE OFFICIALS DESIGNATED BY THE GOVERNORS TO ADMINISTER THE PUBLICLY-FUNDED DRUG AND ALCOHOL TREATMENT AND PREVENTION PROGRAMS.

MR. CHAIRMAN, YOU AND THE MEMBERS OF YOUR SUBCOMMITTEE ARE ALREADY FAMILIAR WITH THE RANGE, COMPLEXITY AND SERIOUSNESS OF THE PROBLEMS WHICH RESULT FROM ALCOHOL AND DRUG ABUSE. THESE PROBLEMS IMPACT ON EVERY SECTOR OF OUR SOCIETY, TRANSCENDING SOCIOECONOMIC LEVELS, RACE, AGE, AND SEX. OVERALL, YEARLY DIRECT AND INDIRECT EXPENSES OF THESE ILLNESSES TOTAL OVER $176 BILLION, BASED ON SUCH FACTORS AS COSTS RELATED TO REDUCED PRODUCTIVITY, MORTALITY, TREATMENT, CRIME, MOTOR VEHICLE CRASHES AND PROPERTY LOSS.

ALCOHOL IS INVOLVED IN 100,000 DEATHS ANNUALLY IN THE UNITED STATES AND IS STRONGLY ASSOCIATED WITH TRAUMATIC INJURIES, THE LEADING CAUSE OF DEATH AND DISABILITY FOR PERSONS UNDER AGE 44. ABOUT ONE-THIRD OF AMERICANS HAVE USED AN ILLEGAL DRUG. APPROXIMATELY TWO-THIRDS OF OUR NATION'S YOUTH HAVE TRIED AN ILLEGAL DRUG BEFORE THEY GRADUATE FROM HIGH SCHOOL. AT LEAST 30 PERCENT OF OUR HOMELESS POPULATION HAVE A SERIOUS ALCOHOL OR OTHER DRUG ABUSE PROBLEM WHICH REQUIRES TREATMENT. IN A SURVEY CONDUCTED BY NASADAD, IT WAS DETERMINED THAT OVER A TWO YEAR

PERIOD FROM FY 1984 TO FY 1986, THE NUMBER OF DRUG CLIENT ADMISSIONS FOR COCAINE ADDICTION MORE THAN DOUBLED.

COMPOUNDING AN ALREADY CATASTROPHIC SITUATION AND OVERTAXED PUBLIC ALCOHOL AND DRUG TREATMENT SYSTEM IS THE TRAGIC DEVASTATION OCCURRING AS A RESULT OF THE AIDS EPIDEMIC. INCREASINGLY, GREATER DEMANDS FOR DRUG ABUSE SERVICES ARE BEING MADE BY THOUSANDS OF INDIVIDUALS WHO ARE INTRAVENOUS DRUG ABUSERS. THESE SAME INDIVIDUALS, HOWEVER, ARE OFTEN INFORMED THAT TREATMENT SLOTS ARE UNAVAILABLE AND THAT THEIR NAMES WILL BE ADDED TO WAITING LISTS OF APPROXIMATELY THREE TO SIX MONTHS. IN FY 1987, THE STATES' PUBLICLY-FUNDED TREATMENT PROGRAMS ADMITTED APPROXIMATELY 100,000 INTRAVENOUS DRUG ABUSERS TO TREATMENT PROGRAMS. THE NATIONAL INSTITUTE ON DRUG ABUSE ESTIMATES THAT THERE ARE BETWEEN 1.2 AND 1.3 MILLION INTRAVENOUS DRUG USERS IN THE UNITED STATES.

THE SECOND-LARGEST AT-RISK GROUP FOR CONTRACTING AIDS IS IV DRUG ABUSERS, THEIR SEXUAL PARTNERS, AND THEIR UNBORN CHILDREN. SEVENTY-SIX (76) PERCENT OF ALL PEDIATRIC AIDS CASES HAVE A PARENT WITH AIDS OR ONE AT RISK OF CONTRACTING AIDS. ALSO, BETWEEN 70 AND 80 PERCENT OF ALL AIDS CASES IN WOMEN ARE LINKED TO INTRAVENOUS DRUG ABUSE, EITHER THROUGH DIRECT USE OF IV DRUGS OR SEXUAL CONTACT WITH AN IV DRUG ABUSER.

ABOUT 95 PERCENT OF INTRAVENOUS DRUG ABUSERS SHARE THEIR NEEDLES AND WORKS AND ARE IN IMMINENT DANGER OF CONTRACTING AND SPREADING AIDS THROUGH BOTH NEEDLES/SYRINGES AND THEIR SEXUAL BEHAVIOR. SINCE WE DO NOT YET HAVE A VACCINE OR CURE FOR THE HIV VIRUS, IT IS IMPERATIVE THAT TREATMENT CAPACITY BE IMMEDIATELY INCREASED TO ACCOMMODATE GREATER NUMBERS OF PERSONS DEPENDENT UPON IV DRUGS.

IN NASADAD'S FISCAL YEAR 1986 STATE ALCOHOL AND DRUG ABUSE PROFILE (SADAP), WHICH IS CONDUCTED ANNUALLY TO COLLECT DATA ON THE STATES' ALCOHOL AND DRUG ABUSE SERVICES, PROGRAMS, RESOURCES AND NEEDS, EACH STATE ALCOHOL AND DRUG AGENCY WAS ASKED TO INDICATE AREAS FOR WHICH RESOURCES WERE NOT ADEQUATE. MOST STATES RESPONDED THAT ADDITIONAL RESOURCES MUST BE OBTAINED TO SUPPORT THE DEVELOPMENT OF ADDITIONAL TREATMENT AND PREVENTION SERVICES TO ADOLESCENTS AND WOMEN AS WELL AS TO THOSE AT RISK FOR AIDS. IN ADDITION, STATES NOTED THE FOLLOWING NEEDS: TO MEET THE SERVICE REQUIREMENTS OF OTHER SPECIAL POPULATIONS, SUCH AS MINORITIES, DUALLY-DIAGNOSED, I.E., ALCOHOL AND/OR DRUG ABUSE AND MENTALLY ILL CLIENTS, AND THE ELDERLY; TO ADDRESS THE LACK OF DETOXIFICATION SERVICES; AND TO INCREASE FUNDING FOR HIRING AND TRAINING OF STAFF.

IN MY OWN STATE OF COLORADO, IT IS ESTIMATED THAT THERE ARE APPROXIMATELY 260,000 ALCOHOL ABUSERS AND 225,000 DRUG ABUSERS. IN FY 1986, THERE WERE 52,556 ALCOHOL CLIENT TREATMENT ADMISSIONS AND 38,882 DRUG CLIENT ADMISSIONS IN COLORADO. AS YOU CAN SEE, THERE CONTINUES TO BE A TREMENDOUS NEED FOR INCREASED TREATMENT CAPACITY.

THE SITUATION IN COLORADO IS CERTAINLY NOT UNIQUE. THERE IS A CONTINUING DEMAND FOR SERVICES AND LENGTHY WAITING LISTS THAT ARE WELL DOCUMENTED AND PUBLICIZED IN OUR LARGEST STATES, CALIFORNIA, NEW YORK, TEXAS AND FLORIDA. HOWEVER, THIS SAME INABILITY TO MEET THE DEMAND FOR TREATMENT EXISTS IN MOST STATES. ILLINOIS REPORTS THAT WAITING LISTS FOR EXISTING ADULT TREATMENT PROGRAMS ARE 4 - 8 WEEKS AND 6 - 8 WEEKS FOR ADOLESCENT TREATMENT. IN MICHIGAN, APPROXIMATELY, 1,000 PERSONS ARE PLACED ON WAITING LISTS EACH MONTH. NEBRASKA HAS ESTIMATED THAT THERE ARE ABOUT 18,000 PERSONS NEEDING TREATMENT SERVICES EACH YEAR WITH CURRENT UNDUPLICATED ADMISSIONS OF ONLY ABOUT 13,000. AND IN IOWA, EVEN WITH SOME NEW MONEY, THERE ARE WAITS OF 4 WEEKS TO

OBTAIN OUTPATIENT TREATMENT SERVICES AND UP TO 3 MONTHS FOR RESIDENTIAL SERVICES.

THE PRESIDENT'S REQUEST OF $509 MILLION FOR THE ADMS BLOCK GRANT WOULD RESULT IN A DECREASE OF $22 MILLION IN PURCHASING POWER FOR EXISTING SERVICES. THIS BUDGET WOULD NOT PERMIT THE NATION TO MEET THE INCREASING DEMAND FOR ALCOHOL AND DRUG ABUSE SERVICES BY THE GENERAL PUBLIC, DWI AND DRUG DEPENDENT OFFENDERS, COCAINE AND CRACK ADDICTS, AND INTRAVENOUS DRUG ABUSERS WHO ARE AT HIGH RISK OF CONTRACTING AND SPREADING AIDS.

WE ARE GRATEFUL TO THE CONGRESS FOR PROVIDING $156 MILLION FOR THE CONTINUATION OF THE ADTR BLOCK GRANT IN FY 1988 DESPITE THE FACT THAT LAST YEAR'S PRESIDENTIAL BUDGET REQUEST CALLED FOR ZERO FUNDING FOR THIS VITAL PROGRAM. ALSO WE ARE PLEASED THAT THE PRESIDENT'S BUDGET FOR FY 1989 REQUESTS $166 MILLION FOR THE ADTR BLOCK GRANT. HOWEVER, DUE TO THE CONTINUING UNMET TREATMENT NEEDS OUTLINED PREVIOUSLY AND THE ALARMING INCREASE IN AIDS AMONG INTRAVENOUS DRUG USERS, NASADAD RESPECTFULLY REQUESTS THAT THE MEMBERS OF THE APPROPRIATIONS SUBCOMMITTEE SERIOUSLY CONSIDER APPROPRIATING A MUCH HIGHER AMOUNT FOR BOTH THE ADMS BLOCK GRANT AND THE ADTR BLOCK GRANT PROGRAMS TO INCORPORATE THE RECENT RECOMMENDATIONS OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS (AIDS) EPIDEMIC.

MR. CHAIRMAN, IT IS ALSO OF GREAT CONCERN TO THE TREATMENT AND PREVENTION COMMUNITY, THAT THE ADMINISTRATION DECLINED TO REQUEST INCREASED AMOUNTS FOR EXPANSION OF THE COMMUNITY-BASED PREVENTION ACTIVITIES OF THE OFFICE FOR SUBSTANCE ABUSE PREVENTION (OSAP). OSAP, CREATED BY THE ANTI-DRUG ABUSE ACT OF 1986 SERVES AS THE FOCAL POINT OF OUR NATION'S ALCOHOL AND DRUG ABUSE PREVENTION ACTIVITIES. THE PRESIDENT'S BUDGET PROVIDES $19.4 MILLION FOR DEMONSTRATION PROJECTS FOR HIGH RISK YOUTH, A $4 MILLION DECREASE FROM FY 1988. THIS LEVEL OF FUNDING WOULD

PERMIT ONLY THE CONTINUATION OF EXISTING PROJECTS AND NO NEW STARTS.

IN LIGHT OF CURRENT EVENTS, THERE IS A CRITICAL NEED TO EXPAND DEMONSTRATION PROJECTS TO FOCUS ON PROGRAMS TARGETED TO REACH MINORITY YOUTH, HIGH SCHOOL DROPOUTS, RUNAWAY YOUTH, AND CHILDREN OF SUBSTANCE ABUSERS. BECAUSE ABUSE OF "GATEWAY DRUGS" (NICOTINE, ALCOHOL, AND CANNABIS) IS ALMOST ALWAYS A PRECURSOR TO THE USE OF DRUGS BY NEEDLES, OSAP MUST RAPIDLY ACCELERATE EFFORTS WITH PARENTS, YOUTH, AND CHILDREN TO PREVENT THE FURTHER INCREASE OF ADDICTIVE/ABUSIVE BEHAVIORS IN ORDER TO STEM THE SPREAD OF AIDS. FOR THESE REASONS, NASADAD RECOMMENDS AN INCREASE IN DIRECT OPERATIONS FOR THESE ACTIVITIES.

MR. CHAIRMAN, NASADAD ALSO SUPPORTS FULL FUNDING FOR THE IMPORTANT RESEARCH ACTIVITIES BEING UNDERTAKEN BY THE NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM (NIAAA) AND THE NATIONAL INSTITUTE ON DRUG ABUSE (NIDA). THE PRESIDENT'S BUDGET WOULD SIGNIFICANTLY IMPEDE CURRENT AND PROSPECTIVE BASIC RESEARCH. FOR FY 1989, NON-AIDS DRUG ABUSE RESEARCH WOULD BE CUT BY $4 MILLION. IN ADDITION TO INCREASED BASIC RESEARCH ACTIVITIES, NASADAD BELIEVES THAT THERE IS A CONTINUING NEED FOR RESEARCH TO DETERMINE THE EFFICACY OF VARIOUS TREATMENTS FOR DIFFERENT TYPES OF PATIENTS. THERE IS ALSO A NEED TO EXPAND CLINICAL RESEARCH STRATEGIES TO DEVELOP MORE EFFECTIVE METHODS FOR TREATMENT OF COCAINE AND OTHER NON-OPIOID DRUG DEPENDENCE, INCLUDING CLIENT TREATMENT MATCHING.

STATEMENT OF VICTOR BLOOMFIELD, HEAD, DEPARTMENT OF BIOCHEMISTRY, UNIVERSITY OF MINNESOTA

Biomedical research and biotechnology in the United States are currently the most advanced in the world, largely because of the basic research and training sponsored by the National Institute of General Medical Sciences. The NIGMS is a remarkable organization. Not dedicated to any particular disease, it supports research on fundamental biological phenomena; but in so doing, it has provided the base on which nearly all disease-specific research and treatment rests.

Perhaps most prominent has been the work sponsored by the NIGMS Genetics Program, which has led over the years to so much of our current understanding of how genes are structured, expressed and regulated. This understanding is now yielding practical results in genetic engineering in biotechnology, and projects currently beginning to map the human genome will surely yield equally practical results in understanding genetic diseases.

I would like to direct particular attention to the equally important, though less publicized, research and training in Molecular Biophysics sponsored by the NIGMS Cell and Molecular Biology Program. Molecular biophysics deals with the structure of nucleic acids, proteins, viruses, and membranes; and with the energetics and dynamics of their transformations. It does so by bringing to bear the tools and concepts of chemistry and physics on biological molecules, to achieve the goal of relating molecular structure to biological function. This union of disciplines has been extraordinarily fruitful, as the following examples show.

- X-ray crystallography by Michael Rossman and his coworkers at Purdue University has recently yielded the structure of the virus for the common cold, a structure which suggests concrete strategies for intervention in the infective process.
- Other x-ray work by Alexander Rich and colleagues at MIT, and Richard Dickerson and collaborators at UCLA, has demonstrated the existence of unexpected structural variants of DNA, which finally begins to make clear the structural basis of the regulation of gene expression.
- Nuclear magnetic resonance (NMR) has been developed by many workers as a tool which is able to determine atomic-level protein and nucleic acid structure in solution under dynamic, functional conditions where crystallization is not possible or desirable. As a result, new insights into the dynamics of protein-drug interactions and molecular aspects of gene control are emerging rapidly.
- In another manifestation, NMR is termed magnetic resonance imaging (MRI). It has introduced a revolution into medical practice, enabling noninvasive localized imaging of the metabolic status of tissues and organs.
- Advances in fundamental theory, in supercomputer power and in computer graphics are making it possible to visualize enzyme structure and to model the combination of proteins with drugs, leading to the prospect of rational drug design.

These developments, and many more like them, are the basis of what has come to be called "protein engineering". This term, paralleling the more familiar "genetic engineering", denotes the use of chemical, physical, and genetic approaches to design proteins and enzymes which have desired properties of reactivity, specificity, and stability. Protein engineering is the goal of the emerging biotechnology industry, which promises to contribute about $100 billion each year to the United States economy within the foreseeable future.

Thus the support over the years by NIGMS of fundamental research has resulted in a host of developments which have practical applications in health-related research and biotechnology. It must be emphasized that this is research not carried out with direct practical benefits in mind. It is research directed at basic understanding of biological processes, and at development of generally useful experimental techniques and theoretical concepts. Yet, as has been demonstrated time and again, basic research has payoffs that are crucial to the solution of practical problems.

Over the years, this committee has demonstrated an support and understanding of basic biomedical research and training for which all of us in the research community are grateful. However, in these days of very tight budgets, there are some points which merit particular consideration.

- Stability and continuity of research funding is extremely important. Most of the budget of a typical NIGMS research grant is for personnel. If a successful research program is not renewed, or if an already funded one is cut back by more than a few per cent, highly trained technicians and graduate students in the midst of their thesis research may have to be let go. This is wasteful, disruptive, and discouraging to young scientists in training.
- Because of uncertainties in research funding, many scientists are forced to spend too much of their time applying for grants. When 50-60% of NIH grant proposals were funded, most researchers were comfortable in submitting one or at most two applications with staggered terms. Now that only about 1/3 of proposals are funded (even though the proposals are every bit as good as before), scientists feel that they must submit three, four or even more applications in order to have a reasonable chance of sustaining their programs. The time

required to do this is particularly devastating to the careers of young scientists. In order to counteract this unfortunate trend, the total number of NIGMS grants available should be maintained in some reasonable relation to the number of qualified academic biomedical scientists.

- Research training also needs considerable expansion. NIGMS provides a major proportion of predoctoral and postdoctoral training grants in biomedical science, and the number of NIGMS trainees has decreased by about 50% since the early 1970s. Return to the earlier numbers is needed for two reasons. First, a significant fraction of the faculty in most university departments are nearing retirement by the early 1990s and will need to be replaced. Second, the developing biotechnology industry will require 1000-1500 new scientists within the next couple of years. Many of these will need expertise in x-ray crystallography, NMR, and protein chemistry, areas supported by NIGMS and currently in very short supply. Paradoxically, at this time when replacement of aging faculty and need for many new researchers in industry demands increasing numbers of trainees, there are fewer graduate students and postdoctorals now in training for biomedical research careers than there were 15 years ago. An expanded training grant program would help to remedy this shortfall.

Because of uncertainties in research grant funding and shortages of training positions, basic research has become a less attractive career to bright young people than it used to be. This clearly will have deleterious consequences for our nation's biomedical enterprise and our competitiveness in the developing biotechnology industry. Stability in research funding, and a training grant program restored to previous levels, should do a great deal to reverse this dismal forecast. It is hard to imagine an investment that will pay greater dividends for our nation's health, economic competitiveness, and international stature.

LETTER FROM FLOYD E. BLOOM, M.D., MEMBER, SCRIPPS CLINIC AND RESEARCH FOUNDATION

June 7, 1988

Senator Lawton Chiles
Attn: Mike Hall
Appropriations Committee
United States Senate
Washington, D.C. 20510

Dear Senator Chiles:

Thank you for allowing me to submit some written testimony for the considerations of the National Institute of Mental Health FY89 appropriation, and with specific regard to their participation in the research into AIDS Dementia. By way of a brief introductory background, I am a Member of the National Academy of Sciences, a former president of the Society for Neuroscience, and the current Chairman of that Society's Government and Public Affairs Committee, and President-elect of the American College of Neuropsychopharmacology. I am also an active bench scientist who has given particular attention to the problems of brain dysfunction in AIDS, and the needs of research in this dreaded epidemic.

I write specifically to emphasize that the nature of the Brain-AIDS problems are immense. The brain and behavioral problems are an especially puzzling aspect of the AIDS infection, since as far as can now be determined, the virus responsible for AIDS is in general terms "neurotropic", the direct observations are that it only physically invades the substance of the brain's blood vessel lining cells, as well as some of the supportive cells, but does not directly invade neurons. How this indirect infection can lead to derangements of thinking, behaving and emotion remain totally unclear, as is the nature of the eventual loss of brain cells prior to death in most cases. Like all problems of behavioral pathology, the goal of research is to understand where and how these changes occur so that we may recognize them early enough to implement preventive or therapeutic manuevers. Thus in my view and in that of many medically oriented neuroscientists, the NIMH AIDS research effort must be soundly rooted in the molecular and cellular antecedents of the behavioral problems of AIDS.

While NIMH may also have an additional role to play in terms of the ADAMHA mission to understand the behavioral and drug-related antecedents that may increase risk for the behaviors that make some individuals at higher risk for exposure to AIDS, the profound nature of the AIDS dementia requires that the NIMH also participate fully in the efforts to understand the actual sites and mechanisms of the virus-brain interaction, and the failure of the immune system to countervene it. It is quite likely that insight into the means by which the brain infection by this virus can indicate behavioral changes may contribute important insight into the pathologic mechanisms of other serious mental illnesses such as schizophrenia and depression.

I would therefore speak strongly in favor of a vigorous participation by the NIMH and its scientific supportees in the research campaign into the neuropathophysiology of AIDS infection of the brain. The NIMH has through its traditional blending of molecular, cellular and behavioral research a unique advantage in this newly discovered malady of behavior. Should you or your staff have any questions I would pleased to be available to you.

Sincerely,

Floyd E Bloom

Floyd E. Bloom, M.D.

STATEMENT OF DR. HARLYN O. HALVORSON, PRESIDENT AND DIRECTOR, MARINE BIOLOGICAL LABORATORY, WOODS HOLE, MA

I appreciate the opportunity to submit this statement describing the work of the Woods Hole Marine Biological Laboratory in biomedical research and training.

The Marine Biological Laboratory-- or MBL as it is known-- was established a century ago as a non-profit scientific institute devoted to research and education in the biomedical sciences. The MBL is the oldest marine biology laboratory in the United States and has been referred to by Lewis Thomas and others as the " National Biological Laboratory without being officially designated as such". For one hundred years, the MBL has sponsored research and teaching programs on cell and developmental biology, neurobiology, sensory physiology and the study of ecology.

An article in the June 1988 Smithsonian describes the MBL this way:

> " This month marks the 101st occurrence of one of the strangest phenomena in natural science: the annual migration of scientists to the Marine Biological Laboratory in Woods Hole,Massachusetts. They will come by the hundreds, from the best universities on the East and West coasts, and from such notoriously landlocked

> localities as Kansas and Switzerland. They will be greeted by another 150 colleagues who, contrary to tradition, work at the MBL all year. ..
>
> Unlike their neighbors at the Woods Hole Oceanographic Institution or the National Marine Fisheries Service down the street, few MBL scientists go down to the sea in ships. For the most part they are content to navigate the world circumscribed by a cell membrane. What they seek are answers to the fundamental questions of life-how nerves send their messages, what makes a cell divide, by what power it divines its role in the organism and knows to organize itself accordingly. Solid, sound, main-stream biology, nothing fishy about it. Except that here in Woods Hole, the sea holds all the answers. "

The scientists who work at the MBL year-round and those who come to study and research in the summer are using marine organisms to explore the biochemical mechanisms underlying disease processes. By studying the biology of marine organisms, scientists are able to obtain basic knowledge to help fight cancer, viral infections, birth defects, parasites and autoimmune diseases such as rheumatoid arthritis. The great abundance and variety of marine organisms found off the waters of Woods Hole makes it possible for researchers to find species with the necessary attributes for many critical biomedical experiments. Examples include:

-sponges: recognition of cellular behavior in sponges that mimics human disease processes so closely that the sponge can now be used to test drugs that are designed to treat inflammatory disease in humans

- mussels: identification of an adhesive in marine mussels that looks promising for the repair of knee and hip injuries

- clown fish: identification of a disease in the red blood cells of the clown fish that is recognized as being similar to sickle cell anemia

-sea urchins and clams: similarities of their eggs and sperm to that of humans permits research related to human fertility

Perhaps the best known example of studying marine life for answers to basic biomedical questions is the use of the giant nerve axon of the squid to study neural transmission. Already such research has led to the development of safer anesthetics and more effective drugs for controlling epilepsy. Ongoing studies are offering new clues to the deadly puzzle of Lou Gehrig's disease, Alzheimers and other crippling neurological disorders.

While higher animal forms may always be required for some types of investigation, research underway at the MBL demonstrates that a great deal of biomedical research can be conducted just as effectively and more efficiently using marine organisms. This is an important consideration in a society increasingly concerned about the use of higher animal forms in basic research.

There are approximately 150 scientists at work in the MBL laboratories year round. Each summer this core group of researchers are joined by some 800 distinguished scientists and advanced students from over 200 colleges, universities and research organizations around the country and the world. With hundreds of the world's most influential biomedical researchers in one place, working side by side, information transfer is expedited, easily crossing scientific disciplines and geographic barriers. It should be noted that the "return" of these summer researchers to their home institutions each fall has far-reaching consequences for advancing the level of research conducted at these institutions and for improving the scientific education of the next generation of researchers and doctors.

In biology, as in other scientific fields, knowledge is expanding at an enormous rate. The pace of discovery has created unprecedented demands for technologically advanced equipment and facilities. This situation creates enormous challenges for a non-profit institute like the MBL. For 100 years, the MBL has played a significant role in fostering the exchange of ideas among the best minds in American and world biology and medicine. We have been able to accomplish this by offering scientists a wide array of marine organisms on which to work and the facilities and intellectual atmosphere in which to perform at their peak. These facilities include the MBL library which is operated in conjunction with the Oceanographic Institution and the National Marine Fisheries Service and which is recognized as one of the world's most comprehensive repositories of biomedical and marine biological information.However, our continued ability to provide the sophisticated level of equipment and facilities required for modern day investigations is in jeopardy.

Last year, a long range planning committee comprised of noted scientists from around the country under the leadership of Dr. Gerald Fischbach, Washington University School of Medicine, St. Louis concluded that the existing core facilities at the MBL are no longer adequate to sustain the technology demanded for advancing biomedical research. Specifically the committee found an immediate need to replace the deteriorating marine life building used for the collection, care and cultivation of marine organisms and also recommended the construction of a new 40,000 sq.ft. modern research laboratory.

This new laboratory, made necessary because existing facilities cannot be converted to accomodate modern molecular research, would focus on the three multidisciplinary research areas of neuro- , cell and developmental biology. The replacement of the marine life building is important because the MBL not only has to be able to provide disease-free organisms for the use of our own researchers but, additionally, the MBL has been responsible for providing over 100,000 such organisms each year for distribution to universities and other research institutions around the country.

The cost of these new facilities has been estimated at $25 million. While we estimate that we can raise about one third of this amount or around $8.6 million, we will need the assistance of the federal government to obtain the remaining funds. To understand why it is necessary for the

MBL to look toward the federal government for some assistance, it must be remembered that although the MBL is providing training and research opportunities for the brightest minds in American biology and medicine, we are a non-degree granting institution. As such we do not have the cadre of graduates that form the basis for obtaining the endowment funds characteristic of colleges and universities. Moreover, the MBL is in fact a second home-- albeit national resource- to most of the researchers using our facilities. It is the primary or so-called "home" institutions of summer researchers who reap the benefit of federal "indirect cost" support, not the MBL.

The cross-fertilization of ideas and scientific interaction fostered at the MBL over the past century has produced important biological discoveries including Albert Szent-Gyorgyi's pioneering work on the energetics of muscle contraction, George Wald's discovery of the role played by Vitamin A in photopigments, and H. Keffer Hartline's discovery of how retinas send visual information via the optic nerve. Research underway at the MBL in the lab of Shinya Inoue (an NIH MERIT award winner) is leading the way in the development of video microscopy, a new biomedical research tool to apply emerging electronics technology to physiology. These are but a few examples of the contributions MBL has made and would like to continue to make toward American leadership in biomedical advances.

Construction of a new marine resources center and an advanced science laboratory is essential to permit the MBL to continue to (1) promote the exchange of information among leading biomedical researchers (2) provide a reliable supply of healthy marine organisms to researchers in universities and research institutions around the country and (3) promote excellence in scientific and medical education across the country. We are presently seeking an authorization for this project and should such an authorization be forthcoming, we would ask for favorable consideration of funding from this subcommittee.

STATEMENT OF THE SOCIETY OF BIOLOGICAL PSYCHIATRY

I am Everett H. Ellinwood, Jr., M.D., and I belong to the Society of Biological Psychiatry which, over its nearly fifty years of existence, has represented the scientific neurobiological approach to assessment and treatment of neuropsychiatric disorders. We have over eight hundred scientific members, all of whom are published in the research journals and who are active scientifically throughout the United States. They also represent individuals deeply involved in the assessment and treatment of neuropsychiatric disorders from a biological perspective.

We are very concerned that a neuropsychiatric and neurobiological scientific approach to the AIDS induced central nervous dementia be explored vigorously in order to reduce morbidity and mortality. AIDS research is now entering its second phase, expanding to include neuroscience. AIDS is not only a viral induced immune disorder, but it is also a neuropsychiatric disorder believed secondary to the infection of the brain by the HIV[4] virus. HIV central nervous system disease is often the precipitating reason for chronic institutionalization in AIDS patients, resulting in a marked increase in the cost of care. The potential for devastating cognitive change with AIDS and HIV infection has been proven, but the underlying neuropathological processes have not been defined. The potential for HIV to attach to or enter the central nervous system was established by scientists at NIMH. They demonstrated that the CD_4 receptor in the human brain is the receptor through which HIV enters the T_4 lymphocyte.

Available neuropathological data do not demonstrate the interneuronal presence of HIV-1. However, examination of Cerebral Spinal Fluid (CSF) from HIV-1 infected individuals indicate that in the earliest stages of the infection the virus is present in CSF, presumably transmitted to the central nervous system by HIV infected monocytes. These patients normally demonstrate HIV antibody reactivity in the early stages of HIV infection. They also have other cerebral spinal fluid abnormalities including increased protein and white cells in association with HIV systemic infection. The studies that have shown that HIV-1 can be recovered form cerebral spinal fluid of the early stages of HIV infection by the viral culture techniques are even more convincing.

Given the data which indicate that HIV enters the central nervous system early in the course of infection, it would follow that neuropsychological abnormalities also appear early in the natural history of the disease. Unfortunately, this assumption has not been systematically evaluated. At present, there is no adequate method to examine how the virus hides behind the blood brain barrier nor to discover what favorable conditions must exist for incubation. Indeed, one must question whether the central nervous system becomes a residual reservoir of the virus. Furthermore, little research has been done on the effect of stress and other associated features of the disease on the neuroimmunological mechanisms. Neuroimmunology is a rapidly expanding but relatively new field that has considerable promise both in the study of AIDS as well as in other neuropsychiatric diseases. Understanding the natural history and mechanisms involved in HIV central nervous system infection will greatly enhance the understanding of other central nervous system viruses that may be involved in a variety of neuropsychiatric disorders, including various degenerative diseases and possibly schizophrenia.

In summary, we would like to recommend that support be given to NIMH and ADAMHA in their attempt to enlarge, significantly, their research efforts regarding neurobiological mechanisms involved in AIDS, AIDS dementia and the neuropsychiatric sequela of AIDS of basic and relevant applied neurobehavioral research. Any assistance your committee can give this direction will accelerate the development of knowledge leading to a reduction of the morbidity of this disease.

On behalf of The Society of Biological Psychiatry, I would like to express our appreciation of your attention to these important concerns. If we can provide further information or advice, please do not hesitate to contact us.

STATEMENT OF THE FEDERAL PROFESSIONAL NURSES ASSOCIATION

I am Hella Frank. I represent the full-time Federal nurses of the Public Health Service who staff the Public Health Units. I appreciate the opportunity to submit testimony to your Committee once again. Unfortunately, however, the critical health issues about which I testified a year ago remain unresolved. These issues include the deterioration of health care provided to Federal employees by the Public Health Service and the job security of the full-time Federal nurses who staff the PHS Units.

After we nurses submitted testimony last year, this Committee adopted Report language containing your finding that it is in the best interest of Federal employees for the Public Health Service to staff government health units with full-time Federal occupational health professional positions. Furthermore, you expressly disapproved the use of contract positions to staff these units. You also disapproved the plan submitted by the Department for the maintenance of health services to government employees. You faulted, as well, the Department's lack of provision for the protection of our rights as career employees. Finally, you ordered the Department to submit a revised plan to meet your objections.

Another year has passed. The Department has totally ignored your directions. PHS continues to replace full-time Federal occupational health nurses with contract personnel whenever a vacancy occurs in our health units.

Qualified nurses are in scarce supply. The nursing shortage has reached national proportions. The Chairman of this Committee, Mr. Chiles, along with Senator Burdick and Senator Inouye, has proposed a national attack on this critical nursing shortage. All three have co-sponsored S.1833, The Medicare Nursing Practice and Patient Care Improvement Act. In co-sponsoring the Bill, Mr. Chiles rightly observed that "we cannot neglect to address the shortage of nurses that threatens the delivery of quality health care services to our citizens."

And yet, in the face of this national nursing shortage, I am sorry to report that the Department's misguided policy of privatization threatens both the quality of Federal employee health care and our job security as well.

The level of full-time Federal occupational health employees nationwide has declined to approximately 190 employees. Meanwhile, the demand for our specialized services continues to grow. Despite your directions, the Department still replaces full-time Federal nurses with contract personnel. Therein lies the problem. The use of contract personnel to staff Public Health Units is the reason for the deterioration in the quality of health care government workers receive in the workplace.

Most contract personnel lack the essential skills of the occupational health nurse. These skills -- according to the American Association of Occupational Health Nurses -- are derived from several disciplines in the health sciences including nursing, medicine, safety, industrial hygiene, toxicology, administration and public health epidemiology.

Furthermore, contract personnel are temporaries. They do not stay long at any one agency. Consequently, there is no continuity in patient care. Contract personnel do not get to know the employees and their environment. They receive little or no supervision or evaluation. They develop no institutional loyalty. They do not care about the future of the occupational health program. And to top it all, they cost the government more than we do. The most recent Department statistics we have been able to obtain demonstrate clearly that there is no cost efficiency gained by hiring contract personnel to replace us.

In fact, the Administration's effort to privatize the delivery of health care to Federal employees by replacing Federal full-time occupational health nurses with inexperienced, transient contract personnel is a costly, illusory failure.

Supply side economics has no place in our health units. The privatization of our specialized occupational health services is directly responsible for the measurable decline in the quality of health care government workers now receive on the job. In our view, privatization is an abdication of responsibility rather than a commitment to better care for Federal employees.

Privatization simply has not worked in the Public Health Service. For instance, in Region III, the scarcity of qualified contract nurses has created a serious personnel crisis. Public Health Units throughout this Region, including those in the Washington, D. C. area, frequently go understaffed. Relief nurses are hard to find. Full-time nurses are over-extended.

Furthermore, no screening process is used to insure that contract personnel are qualified in occupational health nursing. Our records show that when contract personnel are assigned to Public Health Units, the daily census declines. In other words, Federal workers do not use Public Health Units as frequently when contract personnel are on duty there. As a result, employee productivity declines. A loss of confidence has developed. Government workers recognize the poor quality of health care privatizing provides. Federal agencies also realize that the price of privatization is too high.

Those in PHS responsible for the management of the Federal Employee Occupational Health Program are themselves now concerned over agency dissatisfication with contract personnel. There is strong evidence that the process of privatization is causing permanent damage to FEOH's reputation and credibility. PHS management now believes that it is essential to assign at least one full-time Federal professional occupational health nurse to each unit. This assignment is necessary in order for PHS to establish proper liaison with agency management and for PHS to provide on-site occupational health expertise as woll as some supervision over the quality of service provided by contract personnel.

We believe that the assignment of one full-time Federal occupational health nurse to each unit is merely a partial answer to the problem created by the use of contract personnel. The only way to restore the quality of health care Federal employees deserve is to staff PHS units solely with full-time Federal professional occupational health nurses.

Also, Mr. Chairman, we have reviewed a draft of the report which the Department is filing with the Appropriations Committees of both the Senate and House in response to your concerns over the implementation of the Federal employees' health service program. This report is a real disappointment.

Although the report states that the career rights of all FEOH employees will be fully protected, the Department totally ignores the specific direction from this Committee to employ only full-time Federal occupational health nurses to staff PHS units. The Report ignores as well the increased cost and the decline in quality of services caused by the growing use of these contract personnel in contravention of your orders.

Instead, the report concentrates on selling the "new direction" which PHS is determined to take -- providing health consultation to agency managers rather than essential health services to Federal employees. We remain totally skeptical of this PHS program.

We urge this Committee to remain skeptical, too. We urge you to remain critical of PHS's risky policy of privatization and consultation. We urge you to continue your oversight of the Federal Employee Occupational Health Program.

We respectfully request that this Committee once again include language in your Report directing the Department to staff PHS units only with full-time Federal occupational health nurses, to preserve the quality of health care available to Federal employees in the work-place and to protect our job security.

We also request that you direct the Department to submit an annual report on the status of the FEOH Program and the progress made toward staffing PHS units exclusively with full-time Federal occupational health nurses.

Finally, Mr. Chairman, we nurses want you to know how deeply we appreciate your efforts to preserve the quality of health care for Federal employees and we thank you for your concern for our welfare.

Proposed Report Language

The Committee remains convinced that it is in the best interest of Federal employees for the Public Health Service to continue to operate health units throughout the Government under reimbursable agreements and to staff those health units with full-time Federal occupational health professional positions. The Committee repeats its admonition that it does not approve the staffing of these units with contract positions. The Commitee directs that an annual report be submitted by January 31, detailing the status of the FEOH Program, the utilization of full-time Federal occupational health professional positions to staff the health units and the procedures adopted to protect the rights of the career employees who staff these units.

STATEMENT OF THE HEALTH INDUSTRY MANUFACTURERS ASSOCIATION

Mr. Chairman, I am Frank E. Samuel, Jr., President of the Health Industry Manufacturers Association (HIMA). The Association represents some 300 device, diagnostic, and health information system manufacturers. HIMA members produce more than 90 percent of the medical products sold in the United States. As leaders in advancing the state of the art in medical technology, our members have a stake in the workings of Medicare's Prospective Payment System (PPS). We supported the PPS legislation and the specific requirement that an independent commission be established.

The Association has consistently supported ProPAC's modest appropriation request, and we do so again this year. ProPAC has proven itself to be a credible supplier of information, policy analysis, and recommendations to improve Medicare PPS.

Since its beginning, the Commission has worked to improve its process for involving the public in its deliberations. There has been much progress in this area. The Commission has matured from a more limited role in making decisions on recalibration of DRGs and updating the overall payment amounts. It has made a successful transition to broader issues including its annual impact report on the Medicare Prospective Payment System and the American Health Care System. Fortunately, however, ProPAC has continued to deal with some technical issues involving DRG recalibration, outliers, and indirect teaching and disproportionate share adjustments which have very important policy implications.

In its annual report on ProPAC, the Congressional Office of Technology Assessment (OTA) noted the need for the Commission to examine itself and continually review its role in the evolution of PPS and, increasingly, related aspects of Medicare payment. OTA noted that Congressional guidance will continue to be helpful to ProPAC as the Commission reassesses its priorities each year. In its appropriations request, the Commission notes several areas where the Appropriations Committee has helped to provide some guidance to the Commission's priorities.

In reviewing ProPAC's request for Fiscal Year 1989, HIMA strongly supports the Commission's plans for extramural research on the adequacy of Medicare cost report data. The proposed "Cost Data Study" is very much needed in light of ProPAC's Recommendation Number 15 that urges the use of cost report data, rather than charges, to set DRG weights. The Commission notes that the limitations of the cost report data may produce imprecise DRG weights which could redistribute payments among different types of cases and hospitals. HIMA believes that the redistribution is unfair since there is no conclusive data to support the change. A comprehensive study is needed to determine whether cost-based weights are any better at reflecting resource use than charge-based weights. HIMA urges the Commission to consult with the hospital industry in the design phase of the study.

In conclusion, we continue to support the role and contribution of the Commission and its request to this Committee for its FY 1989 appropriations.

STATEMENT OF THE ASSOCIATION FOR GERONTOLOGY IN HIGHER EDUCATION

Chairman Chiles and distinguished members of the subcommittee, this testimony is being submitted on behalf of the Association for Gerontology in Higher Education (AGHE). AGHE is a nonprofit membership organization of over 300 institutions of higher education that conduct research and provide training and education in the field of gerontology. This testimony will address the proposed FY 1989 budgets of the Administration on Aging, Title IV (OAA) programs; the Health Resources and Services Administration, Bureau of Health Professions; the National Institute on Aging; and the National Institute on Mental Health, Mental Disorders of the Aging Branch.

Once again, our country's political leaders must struggle with the dilemma of dividing scarce resources between those programs which have long-term payoff and those programs which have a quick, visible, and dramatic impact on the society and the economy. As an association of educators we must emphasize the need to spend money wisely by adequately preparing for the future. At this time, the federal responsibility for assuring the development of a research base and a supply of trained professionals in the field of aging must be reaffirmed.

We thank you for your support over the past several years and ask that you continue to be advocates for improving the lives of Americans of all ages through the continuation of the unique education, training, and research programs which the budgets of these four agencies fund.

Importance of Aging Education, Training, and Research. We argue that of equal value to service programs for older Americans are the (a) research activities which expand our knowledge about the aging process, (b) the demonstration projects which enable more appropriate and efficient service programs to be designed, (c) educational programs which prepare professionals to work in the field of aging, and (d) continuing education and training programs which upgrade the skills of persons already serving the elderly and their families.

The Department of Health and Human Services' September 1987 report to Congress on Personnel for Health Needs of the Elderly Through 2020, underscores the importance of providing adequate funding for education and training programs in the broad field of aging. According to the report, future demands for health personnel, ranging from aides to medical specialists, will greatly exceed the current and anticipated supply. In order to minimize the impact of this predicted shortage the number of prepared teaching and research faculty (and other leaders) must be expanded as an initial priority. The report states that the current number of educators ranges from only 5 to 25 percent (depending on the field) of the estimated need. While increased funding for education and training programs is essential, resources must also be allocated for ongoing studies and analyses of future personnel needs. As stated in the report: "The dynamic nature of the U.S. society and health care system requires ongoing assessments of the direction and scope of future needs" (page 5).

We would like to thank Congress for recognizing the need for this study, and offer our congratulations to the National Institute on Aging and the Bureau of Health Professions for the excellent document they produced. But unfortunately, this document provides only a partial analysis of personnel needed to meet the diverse needs of an aging population. At this time, we urge Congress to mandate a similar study on personnel for social services needs of the elderly. A coordinated analysis must be made of the future personnel needed to develop and operate housing, nutrition, recreation, and various social services programs for older Americans.

Recommendations for FY 1989.

We are at a critical juncture in the development of resources and personnel required for an aging society. The size of the aging population is expanding so rapidly that this is not the time to curtail research or education efforts in this field. Rather, we must provide sufficient funding for aging education and research so that effective means can be developed to meet the needs of an increasingly "greying America." Without adequate support for these research, education and training programs, manpower needs predicted for the next thirty years will not be adequately met.

AOA-Title IV. This Association is opposed to the Administration's generic appropriation request for all OHDS research and training programs, including Title IV of the OAA. We strongly oppose such consolidation of funds, on the grounds that it would prevent accountability on the part of individual agencies, and obscure program visibility. The recommendation of this Association for Title IV (OAA) is a modest increase of 10 percent to $27,500,000. This small increment in the funding level would partially account for past inflation and serve to bolster the program. **There has been no increase in Title IV funding since FY 1985.** Moreover, the program has had to endure across-the-board funding cuts mandated by Gramm-Rudman sequestration. As a result, in constant FY 1976 dollars, the FY 1986 allocation of $23.9 million is only $12.4 million, a 62 percent decrease from the FY 1976 level of funding.

HRSA-Bureau of Health Professions. This Association is deeply concerned about the Administration's proposed changes, outlined in the FY 1989 budget, for health professions education. It would be a grave error on the part of Congress to enact legislation resembling the Administration's proposed "Cooperative Health Professions Initiatives" program. According to the plan, funds would be awarded to states, institutions, or other entities to promote training of health professionals in geriatrics, family medicine and nursing. The Administration's budget request for this program is $40 million a substantial cut of $169 million from the FY 1988 budget for programs currently operating under the Bureau.

We implore Congress to dispense with this short-sighted and ill-conceived proposal set forth by the Administration. Such a program would not only result in substantial budgetary reductions, but would diminish the Federal government's responsibility for developing an adequate supply of properly trained health care workers. In its place, Congress must enact legislation introduced by Senator Kennedy (S.2229), and its companion piece in the House, to reauthorize the Public Health Service Act with programs that are responsive to the health care needs of our Nation. After passing such legislation, we would recommend that sufficient funding be allocated to effectively carry out the programs delineated under the "Health Professions Reauthorization Act of 1988."

National Institute on Aging. With regards to NIA, AGHE recommends an FY 1989 funding level of 263.5 million. This sum would enable the Institute to fund a total of 847 research grants, including 326 new grants. This proposed budget would also allow for 145 new research training positions, bringing the total number of trainees to 463. In addition, NIA would be able to fund 3 new Alzheimer Disease Research Centers, and 5 first time Geriatric Training Centers. Further, the Institute would be able to enhance its research colonies, including the development of animal models of Alzheimer's, and enhance the intramural research program by adding 2 beds to the clinical center.

Conversely, if the Administration's FY 1989 budget proposal for $204.7 million were enacted all research grants would have to be negotiated down by an average of 14.5 percent, and funding would only be available for 204 new research grants. Similarly, only 44 new and competing training positions would be funded. Finally, the other initiatives mentioned above would not be implemented.

NIMH Mental Disorders of the Aging Branch. The current Administration is trying for a final time to eliminate all clinical training under the auspices of NIMH. The Administration has requested $5 million for clinical training in FY 1989, a $10 million reduction from FY 1988. The $5 million request is part of a plan to phase out clinical training over a three year period. Once again, Congress must not allow the Administration to eliminate this important program. We urge you to maintain at a minimum the current level of funding.

With regards to research training, the Administration's request to increase stipends must be matched by an across-the-board increase of at least 30 percent for research training, in order to maintain the current number of positions. Without such additional funding, a mandated increase in stipends will require a cut in the number of positions to provide for higher individual allowances.

Finally, this Association endorses a modest increase for the research budget of the Aging Branch. We believe that in this era of economic constraint, limited funds must be distributed equitably between research and training.

STATEMENT OF THE PHILADELPHIA GAS WORKS

My name is Robert J. Patrylo and I am the President and Chief Executive Officer of the Philadelphia Gas Works. The Philadelphia Gas Works is the largest municipally owned gas utility and the 26th largest gas distribution company in the United States. We distribute gas to over 500,000 customer within the city limits of Philadelphia.

I would like to thank Senator Chiles and the U. S. Senate Appropriations Subcommittee on Labor, Health and Human Services for the opportunity to submit this written testimony supporting restoration of funding for the Low Income Home Energy Assistance Program (LIHEAP) for Fiscal Year 1989 to the level appropriated in Fiscal Year 1985.

For over 152 years, PGW has been committed to supplying all of its customers with safe and reliable service at the least possible cost. While PGW endeavors to meet the needs of all its customers, it is firmly committed in its efforts to meet the needs of its low income customers.

PGW was instrumental in creating the Utility Emergency Services Fund, one of the nation's largest private fuel assistance funds. PGW has contributed several million dollars in bill credits to the Fund. In addition, PGW has liberal repayment programming for customers with unpaid bills.

One of these programs allows them to pay 5% down on their bill, provided they are income eligible and pay 2% on the arrearage for 24 months, with the balance of the arrearage being forgiven after completion of agreement. PGW has one of the country's largest conservation and weatherization programs, which has served over 35,000 low income households since its inception in 1982.

As you can see, our concern in meeting the energy needs of our low income customers has been foremost in the minds and actions of the entire PGW family.

In an effort to supply you with up-to-date information for inclusion in your deliberations on the 1989 Fiscal Year funding for LIHEAP, consider the following

THE IMPACT OF HIGH ENERGY COSTS

Between 1979 and 1988 the Pennsylvania Public Utility Commission (PUC) reported that the average Pennsylvania home energy bill has increased by 14%, while the average LIHEAP benefit decreased 35% from $340 (1979-1985) to $231 (1986-1988). Additionally, the 1979 average LIHEAP grant covered 28.5% of the energy bill, while in 1988 only 17% of the energy bill was covered by LIHEAP.

PROJECTED ENERGY COSTS

While natural gas and oil surpluses have moderated price increases in recent years, energy costs continue to pose a staggering burden for low income households.

- Low income people pay an average of 16% of their income for energy needs, four times that of the average American family.
- LIHEAP eligible households have an average income of approximately $7,000 compared to $25,000 for the average American household.

NEED FOR LIHEAP

Contrary to the current administration's claims that Americans are better off now, 61% of the 13 million jobs created thus far have yielded less than $7,000 annual wages! This has resulted in more poorer working class families in need of energy and other assistance to survive.

LIHEAP FUNDING

FISCAL YEAR	AMOUNT AUTHORIZED (Billion)	AMOUNT APPROPRIATED (Billion)	AVERAGE CASH GRANT IN PA.
1982	$1.875	$1.875	$319
1983	1.875	1.975*	340
1984	1.875	2.075	305
1985	2.140	2.100	346
1986	2.275	2.010	222
1987	2.050	1.872	243
1988	2.132	1.523	228
1989	2.200	1.187** 1.523 & Cost of Living***	

* After Supplemental Appropriation

** Administration Budget Proposal

*** House and Senate Budget Committees

Since 1984 LIHEAP has not been funded at the level authorized. PGW, along with others is well aware of the Federal deficit. However, we still feel compelled to urge Congress to fund LIHEAP in Fiscal Year 1989 at no less than the level appropriated in Fiscal Year 1988 plus a factor for inflation as agreed by both the House and Senate Budgets.

OIL OVERCHARGE

Congress must not look to the oil overcharge funds to be a quick fix for the LIHEAP program. These funds were never intended to supplant federal funding for the program, but were meant to be an addition.

PGW'S RECOMMENDATIONS

Therefore, PGW urges Congress to support energy assistance and weatherization programs by at least meeting Fiscal Year 1988 authorization for LIHEAP plus inflation. And, in the years to come, increase the level to a level which better addresses the needs of low income home energy users.

Thank you.

STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

The Humane Society of the United States (HSUS), on behalf of our 825,870 members and constituents, appreciates this opportunity to address our concerns about the chimpanzee breeding program funded by the National Institutes of Health (NIH).

NIH'S CHIMPANZEE BREEDING PROGRAM

In 1986, the NIH quietly launched an ambitious breeding program to ensure that a steady supply of chimpanzees will be available for biomedical research for decades to come. Unfortunately, the program raises serious humane issues and fails to address them.

Under this program, the NIH is funding five chimpanzee breeding colonies and five projects aimed at enhancing chimpanzee reproduction.

The HSUS has taken the position that chimpanzees should be phased out of research as soon as possible. Until that happens, any plans for the use of chimpanzees should take into account the unique relationship between human beings and chimpanzees. Chimpanzees have 99 percent of their genetic material in common with human beings. Yet according to documents received under the Freedom of Information Act, the NIH's program does not even attempt to justify the continued need to subject these animals to experiments. The NIH apparently considers the need self-evident. The subject of alternative models to the use of chimpanzees are not mentioned in the documents, much less treated as a subject worthy of study. No types of experiments are classified as impermissable, which is particularly troubling in light of some researchers' desire to investigate transplantation of organs from chimps to humans. No details are provided on the types of experiments that are likely to be conducted on the surplus offspring produced at the colonies. No provision is made for international coordination of research, which would reduce redundancy.

In addition to the documents that describe the NIH's intentions, The HSUS has also obtained copies of the ten grants being funded currently under the program. These documents make disturbing reading for anyone familiar with the lives of chimpanzees in their natural environment, as revealed by observations of Dr. Jane Goodall and others. Chimpanzees are highly social animals with human-like behavioral and emotional features. They travel over large areas. Infants are dependant on their mothers for several years. They are extremely vulnerable behaviorally, emotionally, and even physically to life under typical - and abysmal - laboratory conditions. Infants, when taken prematurely from their mothers and placed alone in cages, are apt to develop abnormally.

The five breeding projects being funded by NIH fail to consistently address these issues. At some colonies, infants will be removed from their mother as early as zero to six months after birth. Some mothers who would normally not conceive or would be abusive mothers are being forced to bear offspring. Many other aspects of these breeding efforts are almost impossible to evaluate from the grant applications. For example, some grants were funded without providing any details on the housing for the animals, which could range from tiny cages to spacious indoor/outdoor enclosures.

The other five projects, designed to enhance reproduction, raise a different set of concerns. They underscore the underlying premise of the NIH's program: that chimpanzees are mere commodities to be grown and harvested. They usher in a "brave new world" of chimpanzee production involving rectal electroejaculation, sperm cryopreservation, superovulation, artificial insemination, embryo collection, and embryo transfer. One project involves transferring chimpanzee embryos into baboons for surrogates.

Aside from concerns about the care and use of chimpanzees, the NIH's program also raises concerns about the disposition of unwanted animals. Chimpanzees are long-lived, expensive to maintain, and easily damaged psychologically by poor housing conditions. Hence the program should provide for the disposition of damaged individuals through rehabilition, and retirement of animals no longer needed. Regulations are needed to prevent facilities from euthanizing unwanted animals for the sake of economy. Few of the funded applications even mention these concerns and none propose solutions. One breeding project matter-of-factly discusses, "culling of reproductively incompetent individuals."

One of the few bright spots in the NIH's program is its potential to reduce the likelihood that the U.S. will resume importing highly endangered chimpanzees from the wild. However, this potential may now be realized as the NIH is reconsidering its policy against the taking of wild chimpanzees for research. The NIH and the awardee institutions clearly have missed an opportunity to come to grips with the difficult humane issues raised by their plans for chimpanzees. This program, as currently implemented, is unacceptable to The HSUS. We are prepared to work with the NIH on a reformulation of the program but will fight to end it if substandard modifications are not made.

Part of the problem is that this program is shrouded in secrecy. Details have been made available only in response to Freedom of Information Act requests, and fulfillment of these requests has been extremely sluggish. But now information about NIH's plans is being conveyed to the public by animal-protection organizations. These organizations and hundreds of concerned individuals are now making their views known to Congress.

In response to this negative attention, the NIH held a closed-door briefing for members of Congress and their staff, on February 19, 1988. Based on what we have learned about this briefing, it focused on the alleged value of chimpanzees in AIDS research. It shed little light on the humane issues raised by the NIH's plans for breeding chimpanzees.

The NIH has spent some $6 million to date on this program. This money has been taken from a NIH discretionary fund earmarked for AIDS research, not chimpanzee breeding.

We ask that if the NIH comes before you to request additional money for the program, that you deny its request until it addresses the humane concerns outlined above. If NIH does not request additional money but attempts to continue funding this unauthorized program with AIDS money, we ask that you restrict such spending.

STATEMENT OF THE AMERICAN HEART ASSOCIATION

The American Heart Association (AHA) is the only voluntary agency in the United States devoting all of its human and financial resources to one goal: the reduction of premature death and disability from cardiovascular diseases and stroke. Coronary heart disease, stroke and related diseases account for almost as many deaths as all other causes of death combined. Annually these diseases are responsible for about one million deaths in the United States. Of the current U.S. population of approximately 239 million, nearly 65 million suffer from some form of these diseases. The cost associated with cardiovascular diseases is astronomical. In 1987 alone, this cost is estimated to be over $80 billion in direct medical expenses and lost output due to disability and death.

Our programs of research, public and professional education and community services all emphasize the the prevention of cardiovascular diseases. Therefore, the federal Office of Disease Prevention and Health Promotion's (ODPHP) and the Centers for Disease Control (CDC) goals are of primary importance to the AHA. Many of our programs complement those of both the ODPHP and the CDC. For example, our Heart At Work program increases employee awareness and knowledge of cardiovascular risk factors and encourages behavior change that will lead to risk reduction. AHA's Heart Treasure Chest program educates elementary school-age children about the cardiovascular system. Our recently announced Heart Rx program assists health professionals in counseling their patients about prudent life-styles that can lead to improved cardiovascular health. It includes booklets, pamphlets, posters and other materials that provide heart healthy advice about smoking, high blood pressure, nutrition and the early warning signs of heart attack and stroke. Finally, AHA's new Physicians' Cholesterol Education Program institutes a long-term educational effort on cholesterol to ultimately reach all primary care practitioners.

The disease prevention and health promotion activities of both the AHA, the ODPHP, and the CDC are aimed at reducing the overall costs of cardiovascular diseases. We are pleased to have the opportunity to provide you with our comments and FY 1989 funding recommendations for the ODPHP and the CDC.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION (ODPHP)

The Office of Disease Prevention and Health Promotion is the federal office responsible for policy oversight and coordination of prevention activities of the agencies of the

Department of Health and Human Services (DHHS); for fostering the development and assimilation of similar activities in the private sector; for providing the services of a national information center to facilitate access to and exchange of information concerning health promotion and disease prevention; and for supporting projects, conducting research and disseminating information about health promotion, preventive medicine and physical fitness and sports medicine.

In 1979 the first Surgeon General's Report on Health Promotion and Disease Prevention, entitled Healthy People, was issued by the ODPHP. This was the first federal document to describe a national commitment to improving the health of this country through disease prevention efforts. It laid the ground work for what has become the cornerstone of the programs of the ODPHP -- implementation of 226 objectives outlined in the 1980 report entitled Promoting Health/Preventing Disease: Objectives for the Nation. The Prevention Policy Branch of the ODPHP is responsible for assessing and reporting on the nation's progress in attaining the objectives outlined in this report. ODPHP's 1986 mid-course review showed that much progress has been made in most of the 15 priority areas encompassed in the 226 objectives, despite selected causes for concern and certain unanticipated problems (e.g., AIDS) at the time the objectives were established.

Currently, a central focus of activity at ODPHP is the monitoring, data tracking, and stimulation of implementation programs in support of the 1990 Health Objectives and the development of a revised set of national health objectives for the year 2000.

Other branches within the ODPHP include the Clinical Services Branch, responsible for promoting the delivery of effective preventive services in clinical settings; the Nutrition Branch, which works to strengthen DHHS's capabilities and national leadership in nutrition research, nutrition monitoring, nutrition services and training, nutrition education, food safety and quality and international nutrition; and the Information Services Branch, which is responsible for ODPHP's National Health Information Center (formerly, the National Health Information Clearinghouse), its publication activities and data management center.

The President's FY 1989 budget includes $3.0 million for the ODPHP. This is a 14.3 percent decrease in the Office's FY 1988 level of funding of $3.501 million. The effects of such a cut in the ODPHP budget would mean the termination of its cooperative agreements program with national organizations in support of implementation of the health objectives and the reduction of planned follow-up activities to the Surgeon General's Report on Nutrition and Health.

A minimal increase in the current services level ($3.472) of the ODPHP, of approximately 5 percent, to $3.646 million will allow for the following: continuation of the current cooperative agreements program with national organizations; maintenance of planned follow-up activities to the Surgeon General's Report on Nutrition and Health; continued support for 1990 Health Objectives process and review; the retention of worksite health promotion initiative, with special attention to at-risk subpopulations of the work force; maintenance of current level activities of the National Health Information Center; continuation of the drafting and refining of national health objectives for the year 2000; and continued support for the new Secretary's Council on Health Promotion and Disease Prevention.

An appropriation of $5 million for the ODPHP would allow for continuation of current activities and the initiation of one or more of the following new initiatives: the National Fitness and Nutrition Public Education Program; the Healthy Cities project to develop and transfer health promotion programs to metropolitan areas; the Communication Health Risks project to educate the public about the safety and dangers of environmental exposures, clinical preventive interventions and personal behaviors; the Healthy Patient project to develop software packages and related materials for health professionals in support of the PHS Guide to Clinical Preventive Services; the Healthy Schools project; the health objectives for the year 2000 tailored for special populations, professions and settings; and the Public Sector and Small Business Worksite Health Promotion Research and Demonstration Program.

CENTERS FOR DISEASE CONTROL (CDC)

The Centers for Disease Control (CDC) is the federal agency of the U.S. Public Health Service responsible for disease prevention and health promotion. CDC works with state and local health departments, other federal agencies, and voluntary, professional and international organizations in assisting during emergencies and in developing programs to understand the causes of disease and prevent their occurrence. In accomplishing its mission of disease prevention. CDC's programs focus on changing lifestyles and other factors that contribute to disease.

CDC consists of the following offices and centers: the Office of Smoking and Health, Center for Environmental Health and Injury Control, Center for Health Promotion and Education, Center for Infectious Diseases, Center for Prevention Services, National Center for Health Statistics, National Institute for Occupational Safety and Health, Epidemiology Program Office, International Health Program Office and the Training and Laboratory Program Office.

CDC's exciting regional and local projects in chronic disease prevention and health promotion include: assisting 37 states and the District of Columbia in tracking risk factors for heart disease: smoking, hypertension, lack of exercise, obesity and cholesterol; supporting a major demonstration project in South Carolina (which has a high death rate from stroke and heart disease) to help state health departments implement the science from the NIH-financed heart disease prevention trials into nationwide community prevention programs; providing leadership and technical assistance to states for standardization and quality control of cholesterol measurements; helping state and local health departments assess health promotion priorities through its Planned Approach to Community Health (PATCH) program; and providing both financial and technical assistance to state departments of health in reducing the impact of chronic disease by intervention methods through its Community Chronic Disease Prevention (CCDP) initiative. These projects represent only the beginning of what CDC could accomplish if they had the resources to nationally launch its chronic disease prevention and health promotion programs.

As the lead agency for prevention, CDC possesses the critical mix of knowledge, skills and existing relationships to form coalitions among voluntary health associations and state and local health agencies to battle chronic diseases. Despite the fact that CDC is the chief federal agency for prevention, the President's FY 1989 budget of $523 million (excluding AIDS) for CDC denotes only $25 million to chronic disease. AHA recommends a $35 million budget (an additional $10 million) for chronic disease. This increase will enable CDC to help states provide leadership in the prevention of cardiovascular disease and other chronic illnesses.

The American Heart Association urges Congress to provide sufficient FY 1989 funding for both the ODPHP and the CDC. Their important prevention and coordination activities must be allowed to continue so that ODPHP, CDC and organizations like the American Heart Association and others involved in preventive health activities can continue to have a downward impact on the mortality and morbidity rates due to cardiovascular and other diseases.

STATEMENT OF THE AMERICAN RHEUMATISM ASSOCIATION

The American Rheumatism Association is the world's largest organization of physicians and scientists specializing in rheumatology research and the care of people with rheumatic diseases. We are pleased to have the opportunity to express our support for an increase in the funding level for the National Institute of Arthritis, and Musculoskeletal and Skin Diseases, (NIAMS), for Fiscal Year 1989.

The ARA advocates, along with numerous professional and scientific organizations and voluntary health groups, overall funding for the National Institutes of Health (including facilities renovation) of $8.47 billion for FY 89. As the committee is aware, this funding level will accommodate an NIH-wide award rate of 41%. For NIAMS, a substantial increase to $224 million will be required in order to achieve a 41% award rate for research project grants in FY 89. By providing our recommended increase in funding for NIAMS, Congress will be able to correct the disproportionately lower award rates at NIAMS, compared to all other institutes. For this country's nearly 40 million people with arthritis, as well as for the nation as a whole, your efforts to correct this situation are critical.

Arthritis and related diseases are among more than 100 different disorders of the joints and connective tissues, including back pain, rheumatoid arthritis, osteoarthritis, systemic lupus erythematosus, ankylosing spondylitis, and gout. One out of every seven people, and one of every three families nationwide, are affected by arthritis and related conditions. In addition, virtually everyone over the age of 65 (the fastest-growing segment of our population) has arthritis to some degree.

Arthritis and rheumatic diseases are among the most common causes of pain, loss of function and disability. They exact a tremendous toll in terms of lifelong pain and suffering and health care expenses for individuals; they also place a great economic burden on society. These diseases have been found to be a leading cause of absence from work in this country. The costs in terms of lost earnings and reduced productivity alone have been estimated in the tens of billions of dollars annually.

Significant new insights have been achieved through study by NIAMS-supported scientists in a variety of areas: For example research based on the techniques of molecular biology, molecular genetics, and immunogenetics is receiving special focus at NIAMS: In the area of rheumatoid arthritis, research has entered a heightened level of activity as investigators begin to use the techniques of molecular biology to develop new insights into the causes of, and treatments for this very serious rheumatic disease. It is hoped that this research can be applied to help tailor drug therapies to genetic determinants, thereby achieving better responses. NIAMS will be sponsoring a workshop focusing on molecular biology and immunogenetics in rheumatic disease research in the upcoming months.

Osteoarthritis is a disease in which many major strides have been made, but for which much more needs to be done. This type of arthritis is one of the most prevalent of the rheumatic diseases. It is characterized by degeneration of the cartilage in a joint, resulting in pain, limitation of motion, and deformity. It may affect one joint, a few, or many. Although osteoarthritis is one of the most common of all chronic diseases, neither the underlying initiating events nor the progression of the disease is, as yet, well understood. Research aimed at gaining a better understanding of general and age-specific epidemiology, etiology, prevention and treatment of osteoarthritis, (particularly through multi-disciplinary efforts) is anticipated by NIAMS. For the 16 million Americans who have been diagnosed as having osteoarthritis, it is particularly important that these efforts be made as quickly as possible. However, the level of effort that NIAMS will be able to support through individual research, fellowships, and career development grants will be directly limited by the level of funding afforded the institute.

Mr. Chairman, we are obliged to bring to your attention a regrettable situation: Since its inception as a separate institute, NIAMS has had an unblemished record of having the lowest award rates and lowest paylines of all the institutes. While this fact indeed speaks to the quality of research proposals being submitted, (i.e. proposals in the "lowest" range of the approved spectrum--the "best" scores--capture all available funding), the negative implications are quite severe: many valuable proposals are not funded, and oppurtunities are irretrievably lost.

For individual research project grants, NIAMS has estimated that it will only be able to fund 25% of approved submissions in the current fiscal year. This is the lowest percentage among all institutes. Most disturbing, under the President's request for FY 89, the percentage is expected to decrease even further! It is absolutely critical that a higher rate of award of these grants be made possible for FY 89. We recommend funding for FY 89 sufficient to support a 41% award rate as an interim step toward funding fully half of approved grants -- the entire range of which presents extremely worthy research opportunities.

ARA's commitment to enhancing research training is equally strong. For quite some time, we have been concerned about the need for an increased number of trainees and higher stipend levels for fellowships. Pending authorization legislation will make this possible. As the segment of older Americans increases, we feel it is especially important to take steps now to ensure that there is a cadre of researchers in rheumatology sufficient to meet this expanded need.

We are also supportive of increases needed to support adequately the variety of other programs which make up the NIAMS research portfolio, including career awards and crucial clinical trials.

The consequences of less than sufficient commitment to these important research activities are far-reaching: Failure to afford necessary support sends a disheartening message to dedicated researchers who may ultimately turn to other fields of study. The discouragement is even more profound for our nation's citizens with arthritis, who must face, every day, a variety of limitations due to reduced independence and function, as well as interrupted social lives, and depression which may result due to these disabling diseases. While it is difficult or those of us blessed with good health to comprehend fully the implications of these diseases, it is obvious that the fact that advances in treatment are being limited significantly due to lack of funding is untenable.

Mr. Chairman, the ARA has determined that the amount needed to adequately address this situation is approximately $224 million.

In the past, the committee has seen fit to provide sound increases above administration budget levels for NIH as a whole, and for NIAMS. Congress has historically appropriated amounts well in excess of the administration's proposals--for FY 87 amounting to a 25% percent increase for NIAMS, (a substantial increase for a newly-organized institute); and for FY 88, a 12% increase over the request. Mr. Chairman, we thank you for your past efforts, and we hope that you will continue to work to achieve funding increases for the important programs of NIAMS.

The American Rheumatism Association submits that increased funding for research efforts directed toward alleviating the disabling effects of those disorders within the purview of the National Institute of Arthritis and Musculoskeletal and Skin Diseases should be a national priority.

The ARA would be happy to provide you with additional expert information and to serve as a resource as determinations are made.

STATEMENT OF THE ATLANTIC EMERGENCY MEDICAL SERVICES COUNCIL

Mr. Chairman, Members of the Committee, I am Harry Teter, director of the Atlantic EMS Council, an organization comprised of EMS directors of the states of New Jersey, Pennsylvania, Delaware, Maryland, Virginia, West Virginia and the District of Columbia. I am here on behalf of the Council to request that this Committee appropriate the full authorization of $85.6 million for the Preventive Health and Health Services Block Grant and $10,000,00 for the Center for Injury Control at Centers for Disease Control. These are much needed dollars going to develop and maintain EMS systems in this country. These systems are critical to combatting one of this nation's greatest health problems, trauma.

Trauma is an injury, blunt or penetrating, which is life threatening to the victim. For the past 8 years the Council has demonstrated to this Committee the gruesome statistics which result from the disease of trauma. Without proper treatment, victims can die or suffer permanent handicaps. With proper treatment, victims can recover and return to productive normal lives. Proper treatment means having an Emergency Medical Services system in place where an accident occurs. These services begin at the scene of an accident with the timely arrival of an ambulance with a trained rescue crew, capable of instantly rendering life-saving services. By means of an EMS communication system, the crew at the scene can receive medical instructions regarding treatment and directions as to where to transport the victim, who is now a patient. Monitoring of this patient begins immediately and critical vital signs are transmitted to the receiving medical facility. The command center will decide the best medical facility to treat the patient, be it the nearest hospital or the nearest trauma center. Finally, in a good system the patient will receive proper rehabilitation and be able to return to a productive life.

Over 100,000 die and 2,000,000 receive life-threatening injuries yearly. Many of these can be averted with proper EMS system. Unfortunately, these systems do not blanket the country; they are only in certain locations. In many areas there are partial systems. As a consequence, many people unnecessarily die or receive permanent handicaps.

The challenge facing all of us in this business is first to prevent the injuries and deaths from ever occurring, and when this is unsuccessful, we then must have proper systems in place providing proper care.

The Atlantic Council wishes to thank you, Mr. Chairman and the members of the Committee for your support of Emergency Medical Services by providing funds for these systems through the block grant. We are also appreciative of the efforts to establish the Center for Injury Control. It is unfortunate that this newly started effort is grossly underfunded. The Administration's request of 1.4 million dollars in no way address the needs of this program. It is our hope that this Committee will recommend an appropriations of $10 million (the authorized amount). Three years ago the National Science Foundation published Injury In America. This excellent study examined the disease of trauma - its cost and what must be done to combat this. The Center for injury Control was created at the Centers for Disease Control to do the job. The report listed many tasks to be undertaken. We suggest that given the toll trauma takes on the people of this country, these dollars are not only justified, they are mandatory. We urge your attention to this program and we implore your support.

It is imperative that trauma be attacked by government on all levels; federal, state and local. I am pleased to report that the Atlantic Council members have been working together for fourteen years to foster complete EMS delivery in our 7 states regardless of state boundaries. We believe in an interstate capability to deliver continuous care when needed. Should an accident occur in one of our states and the proper care facility be in a neighboring state, care can be rendered in both states with no interference. We still have needs to address and HHS funds are much needed to do this. Equipment needs to be replaced, manpower must be trained and retrained.

I am pleased to report that the Council is about to begin a 2-year project to develop a multi-state regional trauma registry. It will be the first of its kind and we will be able to look closely at the interstate operations of our system. We will see the magnitude of our trauma which crosses state borders, the kinds of trauma and how our systems are serving trauma victims in the region. I am pleased the Center for Injury Control is working with us. We hope that we will also be able to pilot some trauma registry work presently being done by the Center. It now has a set of minimum data points for a good trauma registry. We need funds to pilot test this. The Atlantic Council members each have designated trauma centers and we would welcome the opportunity to use the registry in our states, to test it value. This would require some ear-marked funds of approximately $350,000 dollars. It would be a national demonstration and the results could be meaningful to all hospitals treating trauma patients. We ask this Committee to designate this for the Council. I will report to you on the progress of this important project.

It would be wonderful if a vaccine could be developed to eradicate trauma. But that will not happen. We will never entirely rid ourselves of this dreadful disease. As long as we are content to believe trauma will never strike us, we will continue to be blinded to the cure. As long as intoxicated persons drive, as long as seatbelts go unused, as long as we ignore the great advantages of airbags, we will have trauma of epidemic proportions. Behavior patterns seem almost impossible to change. Even if we were to mandate these preventive programs, trauma would still not be totally eliminated. And as long as trauma continues we will need EMS systems. The goal of a blanket of interlocking systems nationwide must be pursued. No matter where we may find ourselves, an EMS system should be there to protect us. We will continue to need the tools to build our systems. And that means money. For this reason we are here today. The Preventive Health block dollar cannot begin to address all the EMS needs; but they help. In addition, CIC needs to continue research into how we can more effectively deliver this care. The Atlantic Council welcomes the opportunity to work with CIC to effect better EMS research. The Atlantic Council members look forward to working with you in any way possible to advance this service both regionally and nationally. We must have complete EMS system across this country; indeed we cannot live without them.

Thank you for the opportunity to present our testimony to you today.

JOINT STATEMENT OF MELDON E. LEVINE, U.S. REPRESENTATIVE FROM CALIFORNIA, AND SAMUEL M. GENENSKY, PH.D., EXECUTIVE DIRECTOR, CENTER FOR THE PARTIALLY SIGHTED

Mr. Chairman and Subcommittee members, I am pleased to appear before you today with one of my constituents and a man of extraordinary talent and courage, and whose work I have come to know and admire, Dr. Samuel Genensky.

Dr. Samuel Genensky and I again come before you to urge the establishment and operation of a national information and referral center for the partially sighted. There is an urgent need for this facility. More than two million Americans are partially sighted. Approximately one-fifth of the partially sighted are also legally blind. Further, those who are legally blind make up more than 76% of the legally blind population.

Historically, and unfortunately even today, partially sighted people are either offered no help at all or are offered services that are at best suitable for the totally blind.

For the past ten years Dr. Genensky and his colleagues at the Center for the Partially Sighted in Santa Monica, California, have offered the partially sighted of Southern California a viable alternative to blindness. They have helped these people to use all of their remaining sensory capabilities, including their precious residual vision augmented with appropriate visual aids, to function as visually and as independently as possible within the framework of fully sighted society.

Dr. Genensky himself is severely partially sighted and has been so since someone in the hospital in which he was born mistakenly put potassium or sodium hydroxide in his eyes thinking that it was silver nitrate. More than 70 percent of the legally blind see better than he does. Yet, he has always been a sight-oriented person. With the help of a pair of binoculars but without the use of a cane, guide dog, braille readers, or any other visual substitution device or technique, he earned a bachelors degree in physics, magna cum laude, from Brown University, a masters degree in mathematics from Harvard University and a Ph. D. in applied mathematics from Brown University. He was a research mathematician on the staff of the Rand Corporation in Santa

Monica from 1958 to 1978 and is the executive director of the Center for the Partially Sighted in Santa Monica, which he and his colleagues founded in 1976-1978. He has written numerous professional papers and has received several awards for his work on behalf of the partially sighted.

It is a special privilege and honor for me to bring Dr. Genensky to your subcommittee. His work, and he himself, have received the highest degree of praise from bipartisian political leaders in California and as well as from a cross-section of citizens throughout the State of California, and it is with a great deal of pleasure that I bring him to your subcommittee.

Testimony in Support of the Creation of a National Information and Referral Center for the Partially Sighted

We come before you today to argue in favor of the creation of a National Information and Referral Center for the Partially Sighted.* Such a Center is needed for the following reasons:

(1) There are more than two million Americans who are partially sighted,

(2) One-fifth of these people are also legally blind.

(3) Those who are legally blind make up more than 76 percent of the legally blind population.

(4) All too frequently partially sighted people tend to receive (a) services that are at best suitable for the totally blind, or (b) no services at all.

(5) The former alternative (4)(a) is tragic for two reasons: (A) Partially sighted people

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* For additional information concerning the partially sighted and other subdivisions and characteristics of the visually impaired population, the reader is referred to Appendix A to this testimony.

need services that encourage and help them to use their remaining eyesight, together with appropriate low vision visual aids, to function as visually and as independently as possible. Services that are useful for the totally blind are based on the principle of visual substitution, rather than visual enhancement. And (B) services geared for the totally blind are not only inappropriate for partially sighted individuals, but are also far more costly than services designed for the special needs of partially sighted people. Hence when services that are appropriate for the totally blind are given to partially sighted people, limited public and/or private resources are wasted.

(6) The latter alternative (4)(b) is also tragic because even though partially sighted people have valuable remaining vision, that vision is limited. Hence they too need assistance, though as pointed out in (5), the help that they require differs from that needed by the totally blind and is far less costly to provide.

Further, experience has shown that partially sighted people are able to perform such sight-intense tasks as:

(1) reading ordinary ink printed material;

(2) writing with a pen or pencil;

(3) moving about alone in even unfamiliar places without the help of a guide dog, a cane, or a fully sighted person;

(4) viewing a computer screen while operating a computer; and

(5) looking at a chalkboard and taking notes on or copying what is seen on that chalkboard.**

All these partially sighted people need to accomplish these tasks are:

(1) prescription of appropriate low vision visual aids;

(2) thorough training in the proper use of those visual aids; and

(3) the will to utilize them.

Although few in number, there are:

(1) optometrists and ophthalmologists in private or group practice who are knowledgeable and experienced in low vision visual care and who include such care in their practices;

(2) low vision clinics that are staffed by such eye care doctors; and

(3) a small number of comprehensive visual rehabilitation centers that provide a wider spectrum of adjunct services needed by partially sighted people.

** Dr. Genensky, as Congressman Levine has already pointed out, is himself severely partially sighted. Even so, he can perform all of these tasks using various low vision visual aids. Further, experience at The Center for the Partially Sighted and at other comprehensive visual rehabilitation centers and low vision clinics strongly indicates that Dr. Genensky's visual achievements have been matched and even surpassed by other partially sighted people, particularly by those who see visual detail better than he does.

Unfortunately, most partially sighted people are unaware of the whereabouts or even the existence of such services. Experience at The Center for the Partially Sighted in Santa Monica, for example, has shown that as a result of short articles in publications that have a large national circulation the Center has received and responded to over 18,000 requests for information and referrals for assistance from partially sighted people, their friends and their families living in every state in the union.

The National Information and Referral Center that we are urging you to bring into existence would:

(1) collect and update information concerning qualified persons and organizations that provide visual, emotional, mobility, independent living, educational, vocational, recreational, and/or financial services that are of importance to partially sighted people;

(2) make this information known to the partially sighted, to those that serve that population, and to the general public via various National Center publications, as well as via the print and electronic media;

(3) urge the people reached by these publications and media to write or phone the National Center for additional information and for referrals: and

(4) provide the additional information, via the phone or by mail, and make referrals to sources of assistance that are located as close as possible to where the person lives who is to benefit from that assistance.

Genensky and his colleagues at The Center for the Partially Sighted in Santa Monica estimate that the operating cost of the proposed National Center in FY 1988-89, in terms of 1988 dollars, would be approximately $600,000. We are recommending that the Congress establish and fund such a Center for a period of at least five years. (Appendix B to this testimony contains a detailed cost estimate for operating the National Center during its initial year of operation.)

Thank you for giving us the opportunity to appear before your distinguished committee and to make our case in favor of the estalishment of a National Information and Referral Center for the Partially Sighted.

Appendix A

Additional Information Concerning the Partially Sighted and Other Subsets of the Visually Impaired Population

The partially sighted are those people (a) whose best corrected visual acuity in their better eye does not exceed 20/70 but is better than light perception or light projection, and they are (b) those people whose best corrected visual acuity in their better eye does exceed 20/70 but the maximum diameter of their visual field does not exceed 30 degrees.

Less precise, but perhaps more understandable, is the definition that states that the partially sighted are (a) those people who, even with the help of ordinary eyeglasses or contact lenses, could not read newspaper column type when they hold the newspaper at ordinary reading distances of from 10 to 16 inches, but who can do more visually than simply see light and/or determine the direction from which the light is coming; and (b) they are also the people who can read newspaper column type when they hold the newspaper at ordinary reading distances, but their field of view does not fill out the area occupied by a 10-inch diameter dinner plate viewed straight on at a distance of 18.6 inches.

Appendix A

Table 1

ESTIMATES OF VARIOUS SUBSETS OF THE VISUALLY IMPAIRED POPULATION OF THE UNITED STATES - 1985

Age	Partially Sighted	Partially Sighted but not Legally Blind	Legally Blind	Partially Sighted and Legally Blind	Functionally Blind
0-4	6,300	5,000	2,100	1,300	800
5-19	120,700	96,800	36,500	23,900	12,600
20-44	379,400	304,200	103,400	75,200	28,200
45-64	462,000	370,400	121,800	91,600	30,200
65+	1,174,100	941,400	296,100	232,700	63,400
TOTAL	2,142,500	1,717,800	559,900	424,700	135,200

The Legally Blind population consists of Partially Sighted people who are also Legally Blind, as well as Functionally Blind people.

The Partially Sighted population consists of Partially Sighted people who are not Legally Blind, as well as Partially Sighted people who are Legally Blind.

See the attached list of definitions of all the categories used in this table.

Prepared by Samuel M. Genensky, Ph.D.
Revised June 1987
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Table 1 gives the size of various subdivisions of the visually impaired population of the United States in 1985 for a number of age ranges. From that table it can be seen that, for example, in 1985 there were 2,142,500 partially sighted Americans and that 424,700 of them were legally blind. Further, it will be noted that in each of the categories shown in the Table most of the people are older Americans. For example, 1,174,100 of the partially sighted were at least 65 years old, as were 296,100 of those 559,900 who were legally blind.

Dr. Genensky reports that his Center sees partially sighted people of all ages, that more than 70 percent of them are at least 60 years old, and that about 50 percent of the patients are in the age range 70 to 90. Further, comprehensive visual rehabilitation centers in other parts of the nation report similar statistics.

The legally blind who are not partially sighted are known as the functionally blind. That population consists of the totally blind and of those people whose best corrected visual acuity in their better eye is rated either as light perception or light projection.

Persons having light perception are able to see light but they are not able to determine the direction from which the light is coming.

Persons having light projection are able to see light and to determine the direction from which the light is coming.

Persons are said to be legally blind if (a) the best corrected visual acuity in their better eye does not exceed 20/200, or (b) if the best corrected visual acuity in their better eye does exceed 20/200 but the maximum diameter of their visual field does not exceed 20 degrees.

A less precise but perhaps clearer definition states that persons are legally blind if (a) even with the help of ordinary eyeglasses or contact lenses, the most that they are able to read on the ordinary Snellen Eye Chart at a standard distance of 20 feet is the big E, and (b) they are also legally blind if with those eyeglasses or contact lenses they are able to read more than the big E on the Snellen Eye Chart at a distance of 20 feet but their visual field would not fill out the area occupied by a 10-inch diameter dinner plate viewed straight on at 28.3 inches.

Persons are visually impaired if they are either partially sighted or functionally blind.

Persons are fully sighted if they are not visually impaired.

Appendix B
Table 2
Cost Estimate for Operating A National Information and Referral Center for the Partially Sighted in FY 1988-89 Measured in 1988 Dollars

Personnel	Number of Days per Year	Cost	
Directional Data Specialist	260	40,000	
Assistant to the Directional Data Specialist	260	25,000	
Computer Consultant	130	20,000	
Programmer	156	18,000	
Public Information Director	156	21,600	
Assistant to the Public Information Director	156	14,400	
Publications Writer	260	36,000	
Staff Consultants on Contents of Publications			
Consultant 1	104	20,000	
Consultant 2	104	20,000	
Consultant 3	104	20,000	
Secretaries			
Executive Secretary	260	25,000	
Secretarial Assistant 1	260	20,000	
Secretarial Assistant 2	260	20,000	
			$300,000
Fringe Benefits (Estimated at 20 percent of Personnel salaries)			60,000
Computer and Peripherals			25,000
Computer Programs and Supplies			15,000
Telephone Expenses (Including Special Equipment, Installation, Toll Free Number and Monthly Billing)			35,000
Office Equipment (Typewriters, mailing machine, duplicating machine, service contracts, etc.)			28,000
Office Supplies (paper, pens, pencils, paper clips, forms, files, etc.)			20,000
Travel			16,000
Overhead (computed at 25 percent of all the previous expenses less capital expenses and travel)			105,250
Total Cost			$604,250

If we assume that (1) the cost of running the National Information and Referral Center will increase at the rate of 8 percent per year, (2) during the first five years of its operation, the National Center will not need to purchase any additional computers or peripherals, special telephone equipment, or mailing machines, (3) the National Center probably will have to purchase another duplicating machine in the 4th year, a typewriter in the third year and a typewriter in the 4th year, and (4) the computer consultant will be needed only at one-quarter time during the 2nd through the 5th years, then the expected costs of running the National Center in each of the first five years of its operation will be:

Year of Operation	Cost
first	$604,250
second	569,430
third	616,151
fourth	674,261
fifth	717,318
Total Five Year Cost	$3,181,410

STATEMENT OF THE AMERICAN AGING ASSOCIATION

Mr. Chairman, Ladies, and Gentlemen: My name is Denham Harman. I am Executive Director of the American Aging Association (AGE).

I appreciate the opportunity to testify on behalf of the American Aging Association before the Subcommittee on Labor, Health and Human Services, and Education Appropriations of the United States Senate on the need to increase support in the National Institute on Aging for basic biomedical aging research directed to determining the process(es) responsible for aging.

Aging - a progressive sequence of age-related, widespread, more-or-less common changes observed in every individual of a given species - is associated with progressive increases in the chance of disease and death with advancing age which ensures that all members are dead by a characteristic age. This universal phenomena is attributed to the aging process.

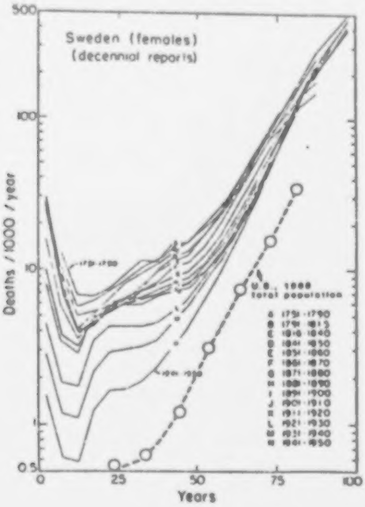

Figure 1. Age-specific death rates of Swedish females in various periods from 1751 to 1950. (Adapted from Jones, H. R.: The relation of human health to age. place and time. in Handbook of Aging and the Individual, edited by Birren, J. E., Chicago Univ., Chicago Press, 1959, pp. 336-363). The superimposed dashed line is the 1985 data for the entire U.S.

The aging process now largely determines the chance of dying in the developed countries. Thus, the chance for Swedish females, Figure 1, decreased significantly from 1751 to 1950 as living conditions improved (better nutrition, housing, medical care. public health facilities, accident prevention, etc.) towards limiting values that increased exponentially with age after a minimum early in life. Similar changes have occurred in the other developed countries; the dashed line in Figure 1 is for the total population of the United States for 1985.

The limiting curve of the chance of death as a function of age, approached as living conditions near the optimum, is the resultant of the irreducible contributions of the environment and disease to premature death and those of the intrinsic aging process which increase the chance of disease and death exponentially with age. The limiting curves for all species have similar shapes; this suggests that they are mainly determined by the aging process rather than by the environment and specific diseases. Curves of the chance of dying for the developed countries are now essentially exponential, i.e., determined largely by the aging process, as illustrated by data for the United States - the dashed line in Figures 1, and 2.

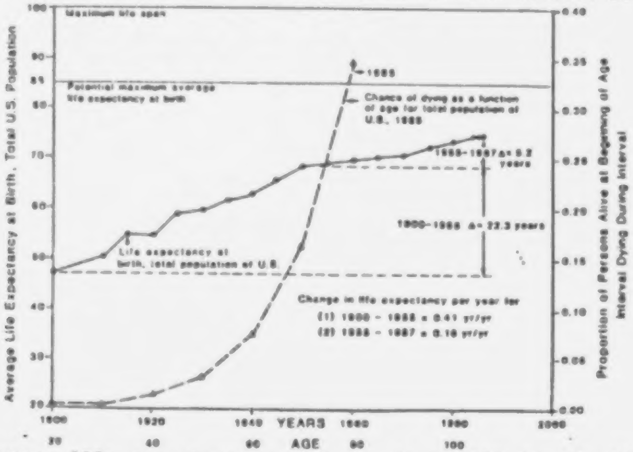

Figure 2. Average life expectancy at birth since 1900 (solid line) and the chance of dying in 1985 as a function of age (dashed line) for the total United States populations.

The contributions of the aging process to disease and death are small early in life. Since they increase progressively with age, at some age it should become significantly more difficult to increase the average life expectancy at birth by further efforts to decrease premature death and should become impossible at a later age. As shown in Figure 2. decreases in causes of premature death since 1900 in the United States resulted in a steady increase in average life expectancy (a rough measure of the healthy life span) from a value of 47.9 years in 1900 to 69.2 years in 1954-1955. After 1954-1955 the rate of increase began to slow, reaching 74.8 years in 1988. Apparently at about 69 years of age the widespread damage caused by the aging process begins to progressively thwart efforts to further reduce premature deaths and to nullify such efforts after age 75-76.

The protean contributions of the aging process to disease pathogenesis, i.e., cancer, atherosclerosis, and Alzheimer's disease, and to non-specific change, obscure the fact that it is now the major risk factor for disease and death in the developed countries and limits average life expectancy to about 75 years.

It is commonly assumed that each disease has a separate pathogenesis. This is only superficially so. The aging process contributes to the pathogenesis of all disorders and becomes a progressively greater risk factor with advancing age. At present about 2.5 billion dollars are being spent per year on cardiovascular disease and cancer alone while essentially nothing is spent on the aging process, the major risk factor for these diseases.

Future significant increases in the healthy life span are likely to be achieved only by reducing the rate of damage production by the aging process. Prospects for doing so are very good. Aside from the fact that mankind wishes to have a longer, healthier life, each year increase would contribute about 1.25 trillion to the economy (assuming 250 million people making an average of $5000 per year); a very good return on research investment. Further, the cost of support programs for older persons should decrease as prospects for increasing the average life span appears better than those for increasing the maximum life span.

The importance of significantly increasing our healthy life span beyond the present value of 74.8 years warrants a major effort by the National Institute on Aging to determine the cause(s) of aging and to utilize that knowledge to our benefit; the formation of the NIA was largely prompted by this problem. I hope that funds can now be designated for this purpose.

STATEMENT OF THE SOCIETY FOR THE STUDY OF REPRODUCTION

My name is Dr. James P. Preslock. I am an Associate Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences at the University of Texas Medical School in Houston, Texas. I am the Chairman of the Public Affairs Committee of the Society for the Study of Reproduction. I am pleased to submit written testimony to the Appropriation Subcommittee on Labor, Health and Human Services, Education and Related Agencies of the United States Senate regarding the budget proposed for the National Institute of Health (NIH) in general, and as it relates to the specific appropriations for the National Institute of Child Health and Human Development (NICHD) for fiscal year (FY) 1989.

Our Society is an international biomedical research society with a membership of over 4,000 domestic and foreign members. The great majority of our Society members are holders of M.D. or Ph.D. degrees, and are on the faculties and staff of numerous medical schools, hospitals, research centers, and undergraduate institutions throughout the United States, and are distributed among 71 nations worldwide. Our Society members are actively engaged in both basic and clinical biomedical research in the reproductive sciences. The primary source of support for our domestic research is through the awarding of competitive research grants through the Competitive Grants Research Program of the NIH and the NICHD. As such, the budgets of the NIH in general, and of the NICHD in particular, is of serious interest and concern to the members of our Society.

Our Society is opposed to the budget for the NIH and the NICHD proposed by the Office of Management and Budget (OMB) for FY 1989. The OMB budget would substantially decrease the number of, and the dollars allocated for, new and competitive renewal grants funded by the NIH including the NICHD for FY 1989. For the NIH overall, the budget proposed by the OMB would decrease the number of new and competitive renewal grants from 6,052 grants to 5,761 grants for FY 1989. For the NICHD, the OMB budget of $418.388 million for FY 1989 would decrease the number of new and competitive renewal grants from 468 grants to 449 grants.

The budget recommended by the OMB for the NIH for FY 1989 would also result in an overall funding rate of only 31.7% of approved new and competitive renewal grant applications. For the NICHD, the OMB budget would result in a funding rate of only 23.2%, which would be one of the lowest funding rates among all of the Institutes within the NIH. Another consequence of the proposed budget would be a substantial negotiated reduction in the funds actually awarded to investigators. The negotiated reduction would be 17.3% for funded new and competitive renewal grant applications. For non-competitive renewal grants the OMB budget would require a negotiated reduction of 10.7% during FY 1989.

Another concern to our Society is the decrease in the number of Research Centers funded by the NICHD which would occur as a consequence of the budget proposed by the OMB. The NICHD currently funds 44 Research Centers, and the budget proposed may result in the elimination of one or more Centers in the Reproductive Sciences. In addition, the OMB budget for FY 1989 would require a negotiated reduction of 16.0% in funds for the remaining Centers within the NICHD.

In our judgment, and as detailed above, the budget of $418.388 million proposed by the OBM for the NICHD for FY 1989 would have a serious detrimental impact upon the members of our scientific Society. We strongly recommend and support a budget of $530.948 million for the NICHD for FY 1989. We believe that this budget is realistic, is attainable, is justifiable and is fundable even in light of the budgetary constraints imposed upon Congress by the Gramm-Rudman-Hollings Budget Reduction Act of 1986.

This budget would permit the full funding, with no negotiated reductions, of 600 new and competitive renewal grants ($182,325/grant; $109.393 million) in addition to 35 grants for AIDS research ($332,857/grant; $11.65 million), at a funding rate of approximately 40% of approved grant applications, for a total cost of $121.043 million for new and competitive renewal grants during FY 1989). This budget would also permit the full funding, with no negotiated reductions, of 1,089 non-competitive renewal grants ($190,376/grant; $207.32

million), in addition to 13 non-competitive renewal grants for AIDS research ($326,923/ grant; $4.25 million), with administrative support of $2.5 million, for a total cost of $214.070 million for non-competitive renewal grants for FY 1989. We estimate that the total cost for new and competitive renewal grants, for non-competitive renewal grants including administrative support, with both competitive and non-competitive grants including specified numbers of grants directed for AIDS research, would cost a total of $335.113 million during FY 1989.

The total budget of $530.948 million which we are proposing for the NICHD for FY 1989 would also maintain the number of Centers within the NICHD at 44, with no loss of any Centers in the Reproductive Sciences. At an estimated cost of $845,000/Center, we propose and support a budget of $37.180 million for NICHD Centers for FY 1989.

The total budget of $530.948 million which we are proposing for the NICHD for FY 1989 would also enable modest and reasonable increases in grant funds for research career development awards, for minority biomedical research support, and for the research training of physicians (total cost: $11.505 million). The budget proposed by the OMB for these programs ($9.399 million) would be unduely restrictive and would prevent any growth in these programs.

Our Society is also in favor of reasonable and justifiable modest increases over the OMB budget for individual and institutional research training (850 trainees, $18.150 million; OMB: 694 trainees, $14.738 million), for research and development contracts including contraceptive development and other initiatives (160 contracts, $36.0 million; OMB: 99 contracts, $21.961 million) and contracts directed towards AIDS (60 contracts, $18.5 million; OMB: 30 contracts, $11.8 million). We also support increases for intramural research not including AIDS ($51.0 million; OMB: $45.3 million), for intramural AIDS research ($3.0 million; OMB: $1.185 million) and for research and management support not including AIDS ($19.5 million; OMB: $18.5 million) and including AIDS ($1.0 million; OBM: $0.5 million). The total funds requested for these programs at the specified support levels is $147.15 million.

In order to achieve these overall levels of support, the total budget supported by our Society for the NICHD for FY 1989 is $530.948 million. We believe that the budget of $418.388 million proposed by the OMB for the NICHD for FY 1989 is unduly restrictive, and will inhibit a reasonable rate of growth and development by the NICHD during the coming fiscal year.

For the NIH as a whole we support a general funding level which would permit the full funding of at least 6,500 new and competitive renewal grants, with no negotiated reductions, and at an overall funding rate of 38-40% of approved grant applications. We also support the funding of a total of at least 20,000 new and competitive renewal, and non-competitive renewal grants by the NIH overall for FY 1989.

The budget which we are requesting and supporting for the NICHD for FY 1989 would provide for a substantial increase in the funding for AIDS research. This emphasis upon AIDS research is justifiable on the grounds that AIDS is a critical immunological disease which is transmitted primarily by the reproductive system through sexual contact. Our proposed budget would also provide for an increase in the funding for the development of newer, more effective and safer contraceptives, with a special emphasis upon preventing unplanned pregnancies and preventing the spread of AIDS and other sexually transmitted diseases. This budget would also provide for increased funds for studies to investigate the causes and treatment of infertility and other reproductive disorders, and for increased studies related to the understanding of basic mechanisms involved in the function and regulation of reproductive systems.

The budget proposed by the OMB for FY 1989 would seriously impair research progress in these critical areas. It is the position of the Society for the Study of Reproduction that these are areas of contemporary importance which, if not adequately supported, will have a serious detrimental impact upon American society both currently, and far into the future.

Thank you for your consideration of our request.

STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The named organizations are dedicated to the health of the pediatric population and ask for your fiscal commitment to those programs and policies which create the opportunity for our children and adolescents to achieve their full potential.

CHILDHOOD IMMUNIZATIONS: Today, we are facing a cost crisis in our childhood immunization program. With the enactment of the vaccine compensation legislation, we sincerely believe that this is a short-term crisis, but it is one that demands your immediate attention. Simple arithmetic gives you the bottom line for necessary funding. But the implications go much further.

For a child to be completely immunized for school entry in the private sector, the vaccine costs alone are $117.06; in the public sector that cost is $69.72. This represents a 28 percent increase over last year. These are out-of-pocket expenses, as immunizations are not traditionally covered by insurance. Discouraging immunizations by making them cost prohibitive is as detrimental to a strong immunization program as is an insufficient supply.

To further complicate this situation, all this is occurring when our immunization rates are already down, particularly in our preschool children. Poor and minority children had the largest drop in vaccination rates, largely due to the fact that the increase in costs have outpaced the increase in federal financial support for the immunization program.

The President has proposed $101.5 million for FY89 for the immunization program. This proposal does not allow funding for state operation of the program (which has always been covered), eliminates support for a vaccine stockpile, and does not provide funds for the new vaccine for bacterial meningitis.

We recommend $110 million for the grants to states, $8 million for surveillance, $5.12 million for the stockpile, $.5 million for the Vaccine Compensation Program (administrative funds), and $12 million for the new meningitis vaccine for a total of $136.62 million.

VACCINE COMPENSATION: In addition to these necessary funds for the immunization program, it is also critical that Congress fully fund the amount authorized for the retroactive vaccine injury cases. Congress must send a strong signal to parents that there is a secure compensation fund available to assist their children and to manufacturers that Congress has assumed some responsibility for vaccine injuries described as no fault in the vaccine injury table contained in the legislation. Without the appropriation of the full $80 million, parents will have no alternative but to pursue a lengthy tort remedy for alleged vaccine injuries and companies will perceive inadequate relief from pending litigation (the major factor in vaccine costs). For Congress to compromise the amount allocated to this item would give the companies little incentive to reduce their liability costs for the next several years. We request $80 million for these cases.

MATERNAL AND CHILD HEALTH BLOCK GRANT: The President has recognized the value of this program and has recommended full authorized funding for FY89. We support this recommendation of $561 million.

NATIONAL INSTITUTES OF HEALTH: One need only review the recent advances of our past to justify increased support for biomedical and behavioral research through the National Institutes of Health (NIH). The NIH supports research into all areas of pediatrics. This research is to: 1) advance our knowledge of genetics, including how best to use that knowledge; 2) investigate fetal development, pregnancy, birth and infant morbidity and mortality; 3) identify the prerequisities of optimal growth from infancy to adulthood; 4) contribute to the prevention and treatment of critical problems for children such as cancer, respiratory diseases and disorders, infectious diseases, and mental retardation, and 5) better understand the psycho-social attitudes of behavior.

Pediatric research should be encouraged throughout the NIH, and the institute which focuses more heavily on children (the National Institute of Child Health and Human Development) should be targeted for increased support. The increases provided to this institute throughout its history are not proportionate with other institutes at NIH. There remains room to "catch up." We recommend $568 million for NICHD and agree with the Ad Hoc Group for Medical Research Funding for $8.221 billion for NIH.

PEDIATRIC EMERGENCY MEDICAL SERVICES: Nearly 18 million children receive emergency medical services annually with as much as 55 percent of all deaths up to age 15 due to injuries. Congress recognized this problem and included authorization for demonstration programs in the Preventive Health Amendments of 1984 to develop standards and guidelines for pediatric emergency medical care. Preliminary data from these programs have provided guidelines around which pediatric emergency medical services systems can be developed, but more needs to be done. These grants remain critical to improving pediatric emergency medical services. We request $5 million for this program.

CHILD ABUSE AND NEGLECT: Child maltreatment is clearly one of the most difficult issues facing our children and our society. Moreover, the problem is self-perpetuating. Without treatment and attention, abused children are more likely to abuse their offspring, and so the cycle continues. We have just begun to implement what we know. Abused children are still never identified; others are never treated; others may be dying. In view of what we now know and the increasing occurrences, we need to develop more effective programs and implement them at the state and local levels and therefore request $46 million.

INJURY RESEARCH AND CONTROL: Injuries remain the greatest killer and crippler of American children over age one and federal research and programmatic efforts aimed at injuries have been minimal. An appropriation of $20 million is needed for CDC to initiate additional research, disseminate its findings, implement the priorities established in the Injury Prevention Act , and to support childhood injury prevention and control program in state and local areas.

PRIMARY CARE TRAINING GRANTS: Pediatricians today treat the medical, the social and the behavioral ills of infants, children and adolescents. The Primary Care Training Grants of the Title VII program were created to specifically train pediatricians for delivery of such primary care and often use ambulatory and community-based clinics and other non-traditional training sites. These sites cannot always be financial self-supportive and therefore are not cost-effective as training programs. This year there were several approved grants within the general pediatrics/general internal medicine program which were not funded. This is only one reason for the federal government to continue its support of such programs. We recommend $22 million for the general pediatrics/general internal medicine program within Title VII.

FAMILY PLANNING: The Public Health Service provides family planning services to improve the availability of such services to all persons desiring them, particularly low-income women. Grants are awarded to the establishment and operation of voluntary family planning projects and for the development and dissemination of family planning information and education. The provision of such services to adolescents remains critical to solving the teenage pregnancy crisis. Too many young people are becoming pregnant; more than 450 babies are born each day to women under eighteen years of age. Maturing young people cannot always get the necessary and appropriate information in a family or school setting, and family planning information could prevent many of these unintended and unwanted pregnancies. This important program should be funded at $155.5 million.

MEDICAID: To build upon the currently mandated and optional eligibility structure we recommend that the Congress 1) mandate coverage for all children and adolescents through 21 years of age and pregnant women living below the federal poverty level; 2) permit states to extend Medicaid coverage to any child and adolescent through 21 years of age or pregnant woman in families with incomes between 100 percent and 200 percent of the federal poverty level for an income-adjusted Medicaid premium no greater than 2.5 percent of family income per child (or pregnant woman) to a maximum of 10 percent of annual family income; and 3) permit states to extend Medicaid coverage to children and adolescents through 21 years of age and pregnant women in families with incomes above 200 percent of the poverty line meeting the out-of-pocket expenditure parameters for an income-adjusted premium no greater than 2.5 percent of family income per child (or pregnant woman) to a maximum of 10 percent of annual family income. Therefore, we support pending legislation which would cover pregnant women and infants up to 100 percent of federal poverty level and recommend an appropriation of $100 million for this program.

RESPITE CARE/CRISIS NURSERIES: The Children's Justice Act authorized monies for respite care demonstration projects and crisis nurseries for infants and young children with disabilities. Respite care has proven to be an effective strategy to reduce stress and keep families with disabled children together. Crisis nurseries will provide appropriate placement for children in need of temporary homes. Reauthorization of this bill is pending; however, we support a recommendation for $20 million for this program.

STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The March of Dimes is especially concerned with four areas of the federal health budget within the jurisdiction of this subcommittee: the Maternal and Child Health Block Grant, Community and Migrant Health Centers, the Childhood Immunization Program, and the research budget of the National Institutes of Health.

None of these programs provides funds to the March of Dimes. The March of Dimes interest is based solely on the belief that funding for these programs is vital to the health of mothers and their babies, and to the prevention of birth defects, low birthweight and infant mortality.

Recent data on maternal and child health underscore the urgent need for an expanded public commitment to preventive health care. For instance, progress in reducing infant mortality has slowed in recent years, dropping only two-tenths in 1985 to 10.6 deaths per 1,000 live births.

In addition, the incidence of low birthweight, a leading cause of infant death, may be growing. CDF reports that the percentage of babies born at low birthweight was virtually unchanged from 1980 to 1984, and actually increased slightly in 1985. It all adds up to a tragic picture. Too many babies are dying. Too many babies are being born at low birthweight. Clearly, the nation must act to reduce these disturbing trends.

What can we do? How can we make sure more babies are born healthy? One answer is prenatal care. Women who get prenatal care are much more likely to have healthy babies than those who get late or no prenatal care.

We know that prenatal care works, and we know that it's cost-effective. The problem is that not enough pregnant women are getting prenatal care. According to CDF, the percentage of infants born to women who received late or no prenatal care increased in 1985. This marked the sixth consecutive year in which this key indicator either failed to improve or worsened.

The nation must take action to ensure that more women get the care they need during pregnancy. The March of Dimes is leading the way with funding and leadership for prenatal care clinics and programs throughout the country. But Congress has a pivotal role to play as well. Expanded Medicaid coverage, combined with increased funding for the MCH Block Grant and Community and Migrant Health Centers, can increase access to health care for millions of poor and near-poor women and children.

In 1986, clinics supported by the MCH Block Grant provided prenatal care to an estimated 447,000 poor pregnant women. Community and Migrant Health Centers provided care to an additional 213,000 pregnant women. All told, nearly one in five of the 3.7 million women who give birth each year obtain prenatal care through one of these two programs.

These clinics that provide prenatal care to the poor are our first line of defense against low birthweight, birth defects, infant death and lifelong handicaps. We urge Congress to support the Administration's proposal of full funding for the MCH Block Grant at $561 million. We urge Congress to appropriate $438 million for Community Health Centers, and $20 million to continue the special infant mortality initiative of the Community and Migrant Health Centers.

Another important federal health program is one that protects children after they are born -- the Childhood Immunization Program. Many of you may recall the time before the development of vaccines against polio and rubella. Healthy children were suddenly crippled or suddenly died. Babies were born blind, deaf or mentally retarded.

The Salk vaccine, developed in 1955 with March of Dimes funding, virtually wiped out polio in this country. Since the late 1960s, when the vaccine against rubella was developed, it is estimated that public immunization has spared more than 40,000 children from birth defects caused by rubella and prevented the need for lifelong care. Another 20,000 children have been saved from miscarriage or stillbirth resulting from rubella.

The nation's investment in childhood immunization is one of the most cost-effective investments we've ever made. Every $1 spent on the Childhood Immunization Program saves an estimated $10 in later medical costs.

Unfortunately, not all children are vaccinated against the major childhood diseases. CDF reports that in 1985, one out of three non-white children did not receive measles, mumps or rubella vaccine. Incidence of both mumps and measles rose in 1986.

In 1988, it will not be enough to simply maintain the same number of vaccinations as last year. To bring unprotected children into the system, and to keep pace with rising costs, an expanded commitment to this program is required. The March of Dimes urges Congress to appropriate $136 million for the Childhood Immunization Program.

And finally, if we are to continue to succeed in the battle against disease, we must have basic medical research.

No one knows this better than the March of Dimes. Over the past 50 years, the March of Dimes has invested hundreds of millions of dollars in medical research. The vaccines, the treatments, the cures and the new knowledge that have resulted have proved the wisdom of this course.

But the March of Dimes can't do it alone. The federal government plays a crucial role through the National Institutes of Health. NIH funds basic medical research, including research on issues critical to maternal and child health through the National Institute of Child Health and Development.

One critical factor in further reducing infant mortality is the prevention of low birthweight. NICHD scientists are currently investigating such important issues as the biochemical signals that initiate labor, the factors that control fetal growth in utero and interventions to prevent preterm delivery. This basic research can lead to important new knowledge--knowledge that can save babies' lives and reduce disabilities.

But the work of NICHD cannot go forward without adequate funding. Under the Administration's proposed budget, the institute would be able to fund only 23 percent of the grants it has approved. This means top researchers would have to go elsewhere for funding or embark on other projects. Some projects that are ready for clinical trials would not be able go forward under the President's recommended budget.

The March of Dimes, therefore, urges Congress to expand funding for NIH and NICHD. We ask that you appropriate $8.2 billion for NIH and $568 million for NICHD.

All of these programs -- the MCH Block Grant, the Community and Migrant Health Centers, the Childhood Immunization Program and NIH and NICHD -- have proven their value to the American people. They are sound investments in preventive health care for mothers and children.

We realize that strengthening these programs will cost money at a time when budgets are being tightened. But we are convinced that failure to invest in primary health care, immunizations and basic medical research will cost much more in the long run. It will cost in lives lost and disabled children. It will cost financially by requiring more money for long-term health care and crisis intervention. The wisest, most humane, most cost-effective course is primary prevention, now. America's mothers and children deserve no less.

LETTER FROM EUGENE A. TRACY, CHAIRMAN AND CHIEF EXECUTIVE OFFICER, PEOPLES ENERGY CORP.

June 15, 1988

Office of Alan J. Dixon
United States Senate
Washington, D.C. 20515

Dear Senator Dixon:

I am writing to enlist your help in a matter of great importance to the people of Illinois, especially people with low incomes. Senate subcommittee mark-up of the national budget for fiscal year 1989 is imminent. Among the items being considered in the budget is funding for the federal Low-Income Home Energy Assistance Program ("LIHEAP").

In January, when President Reagan submitted his proposed fiscal year 1989 budget to Congress, his Administration recommended that $1.187 billion be spent to fund LIHEAP during the coming fiscal year. This amount represents a cut of $344 million -- over 20% -- from the fiscal 1988 LIHEAP funding level, and a reduction of over $650 million from the fiscal 1987 level. I ask that you reject the Administration's proposed LIHEAP funding cut, and support funding this necessary federal program in fiscal 1989 at a level of at least $1.975 billion, the level of funding for fiscal year 1987 increased slightly for inflation. At a minimum, the Senate should approve funding set at $1.6 billion, the level approved by the House Appropriations Subcommittee on Labor, Health and Human Services.

Under the Administration's proposal, Illinois would lose $20 million in LIHEAP funds in fiscal year 1989, after already sustaining a $19 million drop in funds for fiscal year 1988. Applying the existing allocation formula to the Administration's proposed funding level, our state's share of LIHEAP funds would fall from the already reduced level of $88.8 million in fiscal year 1988 (for fiscal year 1987 funding was $105.7 million) to $66.8 million in fiscal year 1989. This $66.8 million figure would represent a loss of almost $39 million, or a reduction of almost 37% from Illinois' LIHEAP funding in fiscal year 1987. While LIHEAP has been one of the very few federal revenue sharing programs in which Illinois' share of federal funds has been relatively large in comparison to other states, Illinois' overall ratio of return of federal dollars in comparison to our state's contributions to the federal treasury has been poor. That ratio will worsen if the Administration's proposed LIHEAP funding cut is adopted.

Peoples Energy Corporation is acutely aware of the harm which would result from the proposed cut in LIHEAP funding. Peoples Energy is the holding company for two Illinois gas distribution utilities, The Peoples Gas Light and Coke Company ("Peoples Gas") and North Shore Gas Company ("North Shore"). A reduction in LIHEAP funding would result in additional hardships to many of our distribution companies' low-income customers. In the City of Chicago, which is Peoples Gas' service territory, there are approximately 120,000 low-income natural gas customers. Even in its relatively more affluent service territory, North Shore also has many low-income customers. Such customers have difficulty paying their utility bills, even with the help they have been receiving from state programs financed with LIHEAP at previous funding levels.

In Illinois, LIHEAP funds help finance the Illinois

Home Energy Assistance Program ("IHEAP"), and the Illinois Home Weatherization Assistance Program ("IHWAP"). Under these humanitarian programs, low-income Illinoisans can obtain grants which enable them to maintain essential utility service for their homes and to weatherize their homes against Illinois' harsh winters.

Even at peak levels of federal LIHEAP funding in prior years, Illinois' IHEAP and IHWAP programs did not have enough funds to help all Illinoisans who qualified for the state programs. In Chicago, IHEAP and IHWAP grant funds have typically run out before all qualified applicants have been helped.

Peoples Gas' experience in fiscal year 1988, as compared to prior years, demonstrates the adverse effect of the LIHEAP budget costs for that period. As of May 31, 1988, the customers of Peoples Gas have received only $6.3 million in IHEAP grants, a reduction of $1.4 million from the comparable amount for May 31, 1987. The number of Peoples Gas' customers who have received grants before funding has run out has also decreased. Funding for IHEAP for Chicago was exhausted in May 1988. As of May 31, 1988, 27,850 of Peoples Gas' customers had received IHEAP grants. This compares to 33,619 as of May 31, 1987, a reduction of almost 6,000 customers.

Let me add that the problems many Peoples Gas and North Shore low-income customers experience in paying their utility bills persist despite the significant progress our distribution companies have made in stabilizing and even reducing their rates to customers. Unit rates for service to small residential customers in Chicago today are almost 30% lower than in October, 1984, which was just after Peoples Gas' last rate increase took effect. Our companies have worked hard to keep down their costs. But for low-income customers the benefit of lower rates has been offset by LIHEAP funding cuts.

The situation will worsen if LIHEAP's funding level is further reduced for fiscal year 1989. Oil overcharge funds -- those already disbursed to the states, and those yet to be distributed -- cannot make up for the cut in LIHEAP funding proposed by the Administration. The amount of money which Illinois receives from LIHEAP and uses to fund IHEAP and IHWAP will shrink further, and many people in our state will suffer.

In addition to IHEAP, Illinois has instituted a program designed to assist persons particularly in need of financial assistance to pay energy bills -- customers with household incomes equal to or less than 125% of the Federal poverty level. That program, the Illinois Residential Affordable Payment Program ("IRAPP"), is the only program under which direct assistance to low income persons is provided from oil overcharge funds. Forty million dollars of oil overcharge funds have been dedicated to subsidizing the participation of indigent customers in IRAPP. If LIHEAP funds were reduced, the $40 million would run out more quickly. No alternative source of funding has been determined once the $40 million has been exhausted. Consequently, reduction in IHEAP funding would shorten the time period during which IRAPP would be available to assist low-income customers.

Reduced LIHEAP funding, and the resultant loss in federal money for Illinois' IHEAP and IHWAP programs, would create an unpleasant set of alternatives for the people of Illinois. A reduction in IHEAP and IHWAP grants could mean that many low-income utility customers could be without heat and other essential energy services. To remedy this situation, the Illinois General Assembly would have to increase state

IHEAP and IHWAP funding, and thereby place an additional burden on the state's taxpayers.

The people of Illinois should not have to face these unpleasant and unfair alternatives.

Very truly yours,

E. A. Drecy

STATEMENT OF THE CONJOINT COMMITTEE ON DIAGNOSTIC RADIOLOGY

My name is Douglas Maynard. I am Chairman of the Department of Radiology, Bowman Gray School of Medicine, Wake Forest University. I also currently serve as President of the Society of Chairmen of Academic Radiology Departments (SCARD).

I am here on behalf of the Conjoint Committee on Diagnostic Radiology for which I serve as Chairman of the Executive Committee.

By way of background, the Conjoint Committee is composed of representatives from the American College of Radiology, the Association of University Radiologists, and the Society of Chairmen of Academic Radiology Departments. The idea of drawing these organizations together for a common purpose was conceived in 1978. And while our field is noted for the rapid pace of new knowledge and innovations it generates, that common purpose has remained clear and steady: to promote and support the advancement of diagnostic radiology research and education.

Mr. Chairman, over the past 50 years the advances in medicine have been truly remarkable. To cite a few: increase in life expectancy, the development of "cures" for many types of cancers, and the elimination of many communicable diseases. The advances have been accomplished by extensive basic and clinical research conducted by faculty in the basic sciences, as well as in all medical disciplines.

But each improvement in health care raises our horizons. Each scientific advance highlights the remaining challenges.

The field of diagnostic radiology has played a significant role in these advancements and has itself experienced more dramatic changes in the past 20 years than any other specialty in the field of medicine. Today medical imaging procedures account for, or contribute directly to, the final patient diagnosis in more than 75 percent of all hospital admissions. These procedures have rapidly extended to the outpatient environment during the past 5 years.

At no time in the past has medical imaging offered more opportunities for research that could directly enhance our ability to diagnose disease.

In large part, this rapid evolution and the promise it holds for the future are the result of the development of new technologies as well as improvements in existing ones. Such areas as nuclear medicine, computed tomography, ultrasound, nuclear magnetic resonance imaging, and what is being called "filmless" radiology are leading this new progress in diagnostic medicine.

These advancements extend well beyond the bounds of a single medical discipline or, for that matter, a single research institute. Diagnostic radiology truly crosses the boundaries of every other medical discipline from pediatrics to geriatrics, from medicine to surgery, from family practice to organ transplantation.

The achievements, the promise, and the potential of diagnostic radiology cut across the whole spectrum of medicine and health -- from diagnosing congenital heart disease in infants and children to developing techniques for the early detection of osteoporosis or cancer of the breast. Medical imaging aids in the diagnosis and follow-up of patients with such diverse problems as brain tumors, coronary artery occlusion, lung infections, trauma, degenerative disc disease, just to name a few.

Looking ahead, the use of multiple new technologies such as magnetic resonance and positron emission tomography for creating images of the brain holds exciting new hope that we may soon have reliable diagnostic tests for Alzheimer's disease and other forms of dementia.

These new technologies can produce cross-sectional images, or "slices," of the brain. These images reveal precise anatomic, physiologic, and metabolic information that cannot be obtained by standard x-ray techniques. Employing computer processing, the radiologist is also able to reconstruct an accurate three-dimensional image of the brain. In addition to producing a visual image, these new techniques are also capable of producing quantitative data about the characteristics of the tissue being examined.

Few would disagree that diagnostic radiology could hold the answers to many of the diseases and disorders that threaten so many lives. Where we run into a problem, Mr. Chairman, is in moving this new and wonderful technology from the basic laboratory to the clinical research phase and from there into routine clinical applications. And as you know, all the new technologies in the world will count for little if we cannot get them out of the research laboratories and into the community.

I would like to emphasize that the requirements for research manpower in the radiological sciences have never been as great as at the present time. If we hope to fulfill the promise of these new techniques, we must increase the number of radiologists involved both in clinical and basic research.

The NIH supports thousands of postdoctoral research fellows. In a recent appearance before the House Labor-HHS-Education Subcommittee, Dr. James B. Wyngaarden, Director of the National Institutes of Health, reported that there were currently only five postdoctoral research fellows in diagnostic radiology supported by NIH and that there is currently an undersupply of career-oriented research radiologists. We agree with him and would like to help develop a strategy to rapidly increase that number.

Dr. Wyngaarden also reported that no diagnostic radiologists are currently serving on any of the NIH's 14 national advisory councils. We believe that because diagnostic radiology closely relates to nearly every other medical discipline, the selection of appropriate and qualified diagnostic radiologists to serve on some of these advisory councils is of paramount importance.

Recommendations

To these ends, the Conjoint Committee recommends the following:

- o Expand the number of training slots allocated under the National Research Service Awards and Physician/Scientist programs for young investigators in diagnostic radiology.

- o Establish and fund a separate, identifiable radiology research laboratory at the NIH to allow the development of a strong intramural research and research-training program.

- o Create a coordinating committee to serve as a central focus on diagnostic radiology within the NIH and to be a catalyst for the various institutes that conduct imaging research.

- Appoint qualified, distinguished diagnostic radiologists to NIH study sections and advisory councils.

Thank you, Mr. Chairman, I would be glad to answer any questions you may have.

STATEMENT OF THE COMMISSIONED OFFICERS ASSOCIATION

Mr. Chairman and Members of the Committee, the Commissioned Officers Association (COA) appreciates the opportunity to present its views and recommendations on several provisions in the Department of Health and Human Services' (DHHS) FY 1989 Budget that, if approved by the Congress, will adversely impact continued use of Commissioned Corps personnel in fulfilling the nation's health mission.

We believe these provisions must be carefully examined by the Committee within the context of Secretary Bowen's proposal for REVITALIZATION OF THE COMMISSIONED CORPS which was implemented in FY 1988. The major purpose of that proposal is to delineate specific management activities to be undertaken to improve the effectiveness, efficiency and productivity of the Commissioned Corps.

Several provisions in the DHHS budget are of concern to the COA. It is our belief that they are designed to systematically erode the strength and vitality of the Corps to the point where its effectiveness will be seriously diminished. At the very least, they will undermine the good results already apparent from Secretary Bowen's revitalization process. Candidly, the COA was astonished that the Administration, at the bidding of the Office of Management and Budget (OMB) persists in sending these worn-out and unacceptable provisions to the Congress. The COA urges the Committee to reject them as you have done in the past.

An identification of the OMB proposals in the FY 1989 BUDGET APPENDIX, together with discussions and recommendations, follows:

I-K25 - Retirement Pay and Medical Benefits for Commissioned Officers

For retirement pay and medical benefits for Commissioned Officers, OMB has eliminated the "such sums as may be required during the current fiscal year", and proposes instead for FY 1989 the sum not to exceed $102,687,000 and an additional $5,000,000, if necessary. Further, it proposes for FY 1990 the sum not to exceed $105,712,000 and an additional $5,000,000, if necessary.

In its determination to eliminate the open-ended "such sums as may be required" language, OMB proposes a two-year appropriation, with a $3,025,000 increase for the second year, and an additional $5,000,000 for each fiscal year, if necessary.

The retirement and medical benefits appropriations approved by Congress for the Public Health Service has, for many years, been an open-ended and indefinite appropriation specifiying "such sums as may be required". This method, together with reasonably accurate annual projections and careful management of the rise of the entitlement, has proved to be satisfactory.

It should be noted that the Congress, in its wisdom, rejected a similar provision in FY 1988.

Recommendation: That the Committee reject OMB's proposal and restore the language which would specify "such sums as may be required".

I-K40 - Sec. 203 - Imposes a Ceiling on Reserve Corps Officers Serving in the Commissioned Corps

The OMB has reinstated a proposal that initially appeared in the DHHS' FY 1988 Budget which sought to place a ceiling on the number of Reserve Officers serving in the Commissioned Corps by requesting a limitation of 3200 for such officers.

The PHS Commissioned Corps is a uniformed service personnel system which has served the PHS and the nation's health mission since the early days of the country. The structure of this uniformed service is very similar to that of the other uniformed services; Army, Navy, Air Force, Marines, Coast Guard, and National Oceanic and Atmospheric Administration (NOAA). The PHS has an active Reserve Corps which provides non-career officers with periods of service which typically run from one to five years. These active reservists contribute substantially to the ongoing efforts of the Regular Corps - a career dedicated contingent. The Reserve Corps can be easily expanded and reduced based on the program needs of the PHS. The Reserve Corps has traditionally provided one-third to two-thirds of the combined active duty strength of the Commissioned Corps.

The COA wishes to emphasize to the Committee that the ceiling issue is not related to the budget deficits in any way since all active duty officers must be covered by a real personnel ceiling under regular appropriations just like any other employee.

Mr. Chairman, a statutory limitation on the number of PHS Commissioned Officers who can be appointed to the Reserve Corps would diminish management's ability to attract and retain a stable cadre of top professionals to meet the continuing program needs of the PHS. The proposed ceiling of 3200 is approximately 50 below the current active duty strength of the Reserve Corps. This is contrary to the goals of the Secretary's proposal for revitalization of the Commissioned Corps.

Recommendation: That the Committee reject the OMB proposal to establish a ceiling of 3200 for the PHS Reserve Corps.

I-K41 - Sec. 208 - Mandates that the Combined Pay and Benefits of PHS Corps Officers shall not exceed 110 percent of the Executive Level II annual rate of Basic Pay

This is a discriminatory pay provision that would inhibit managerial ability to freely assign competent officers to key posts. Further, such a provision does not exist in the military pay structure and is without justification.

I-K41 - Sec. 208 - Pay Restrictions Imposed on Commissioned Corps Physicians and Dentists Assigned to Administrative or Managerial Posts

This provision would seriously restrict PHS authority to assign newly-recruited Corps physicians and dentists to posts commensurate with their skills and abilities. Moreover, the provision would authorize the Secretary, on a discretionary basis, to extend special, revised special or continuation pay to any physician or dentist who, through promotion or reassignment within the Corps, is assigned to an administrative or managerial post.

We are deeply concerned that PHS management flexibility to assign Corps physicians and dentists, whether they be newly-recruited or long-term officers, to the wide array of posts in the PHS will be seriously jeopardized if this discriminatory pay provision is approved by the Congress for FY 1989.

If the Administration believes the continued assignment of PHS Commissioned Corps officers should somehow be modified, we are adamant in our view that they incorporate their multiple proposals into a legislative package for submission to the substantive legislative committees with jurisdiction over health matters. Full and open hearings should be held on such proposals with testimony from the many professional organizations that comprise the health community. Through this process, the Congress could then arrive at an informed judgement on the role of the PHS Commissioned Corps vis-a-vis our nation's health effort.

It should be noted that the Congress, in its wisdom, rejected a similar provision in FY 1988.

Recommendation: That the Committee reject the two foregoing pay restrictions proposed by OMB.

Mr. Chairman, our organization appreciates the thoughtful work of this Committee in providing adequate funding for health programs that are so important to the physical and mental well-being of our nation's citizens. We are hopeful that you will be able to accept our recommendations with respect to the several budget provisions discussed in this statement.

STATEMENT OF THEODORE W. VAN ZELST, PRESIDENT, MINANN, INC.

Mr. Chairman and members of the Committee, my name is Theodore W. Van Zelst. I am presenting this testimony for the record as president of Minann, Inc., a foundation which has been active in the past five years on matters related to an emerging disease recently defined by the Centers for Disease Control as Chronic Fatigue Syndrome (CFS). In the past, this disease had been referred to as Chronic Epstein-Barr Virus Syndrome (CEBV).

"If it weren't for the emergence of AIDS, Chronic Epstein-Barr Virus Syndrome (CEBV) would be the disease of the decade." That statement was the first line in an article on CEBV-CFS by Paul J. Donald, M.D., appearing in the Bulletin of the American Academy of Otolaryngology-Head and Neck Surgery, March 1988. Dr. Donald stated, "Although some controversy still exists as to the actual existence of the disease, there is growing air of general acceptance of the syndrome by the medical community at large."

In the March 16, 1988 House Hearing for the Department of Health & Human Services, Dr. James Mason, Director, Centers for Disease Control, under the heading 'Emerging Diseases' stated: "The Center for Infectious Diseases is addressing newly recognized infections or vectors of potential public health significance... Chronic Fatigue Syndrome possibly associated with the Epstein-Barr virus is an illness affecting an unknown number of individuals in the U.S. ...We are studying these newly emerging public health problems and developing intervention measures for prevention and control." CFS was one of the six 'emerging diseases' mentioned by Dr. Mason.

Joseph Brewer, M.D. Infectious Disease Section, St. Luke's Hospital, Kansas City commented: "Chronic Fatigue Syndrome represents a very complex and serious health problem for which there is an urgent need for more clinical and basic science information. In the Midwest we are seeing a dramatic increase in newly diagnosed cases and many of these patients are extraordinarily ill."

Chronic Fatigue Syndrome is a collection of signs and physical symptoms that are identifiably distinct from other diseases. Its cause is unknown. It is a multi-system disorder requiring a multi-disciplinary approach. It may affect many body systems including nervous system, immune system, lymphatic system, sensory system and digestive system.

When the disease first received widespread attention three years ago, many experts believed it was associated with the Epstein-Barr virus, a common virus that causes mononucleosis. High levels of antibody to this virus often were considered a sign of the illness. The disease was called Chronic Epstein-Barr Virus Syndrome. But many experts now believe that Epstein-Barr virus was a false lead. Some victims show no signs of that virus, while others have high levels of antibodies to the viruses that cause measles, genital herpes and cold sores, among other ills. Technology now indicates that causality may involve more than one factor including a second virus, bacterial agent, a hereditary component or exposure to some environmental toxin(s). Research continues in these areas.

The Chronic Fatigue Syndrome is formally named and defined in an article in the Annals of Internal Medicine, March, 1988 (Gary P. Holmes, M.D. et.al., Chronic Fatigue Syndrome: A

Working Case Definition.) The article is authored by a group of public health epidemiologists, academic researchers, and clinicians. Abstract of their statement:

> "Chronic Epstein-Barr virus syndrome (CEBV) is a poorly defined symptom complex characterized primarily by chronic or recurrent, debilitating fatigue combined with various combinations of other symptoms, including sore throat, lymph node pain and tenderness, headache, myalgias, and arthralgias. Although the syndrome has received much recent attention and many patients have been diagnosed with it, CEBV has not been consistently defined. Despite the name of the syndrome, both the diagnostic value of EBV serologic tests and the proposed etiologic relationship between EBV and the patients who have been diagnosed remain doubtful. We propose a new name for CEBV--chronic fatigue syndrome--that more accurately describes this symptom complex as a syndrome of unknown etiology characterized primarily by chronic fatigue. We also present a working definition for CFS that is designed to improve the comparability and the reproducibility of clinical research and epidemiologic studies, and to provide a rational basis for evaluating individual patients who have chronic fatigue of undetermined etiology."

According to the new definition of Chronic Fatigue Syndrome, two ma[illegible]eria for people suffering from the syndrome are: (1) Debilitating fatigue that does not go away with bed rest, has lasted at least six months and reduces a person's average daily activity by more than 50%. (2) The elimination by doctors, through physical examination, laboratory tests and a patient's history, of a long list of diseases that could cause similar symptoms. In addition, a patient must show signs of 8 or more of the following 11 symptoms: mild fever; sore throat; painful lymph nodes; unexplained generalized muscle weakness; muscle discomfort or pain; fatigue lasting more than 24 hours after exercise; headaches; joint pain or swelling; a neuropsychologic complaint such as depression, confusion or inability to concentrate; sleep disturbance; or onset of debilitating fatigue over a few hours or a few days. Leading physicians at the NIH, NIAID and CDC have all stated their belief that this syndrome is real and that it is "organic". Medical research has determined that this is a disease of immune dysfunction. An article in the Journal of Immunology, November 15, 1987, reports that dramatic abnormalities have been found in the immune systems of CFS patients.

SUPPORT GROUP ACTIVITY

There has been a tremendous grass roots effort by patients afflicted with CFS. More than 320 active support group leaders, with an excess of 12,000 members assist patients. They give moral support, distribute current research reports and provide lists of physicians who have a familiarity with the illness. Many support groups communicate in newsletter form to their own members and exchange newsletters across the country.

What's Being Done? — A Sampling of Research Activity

"There is evidence that people with Chronic Fatigue Syndrome have immune system dysfunction which puts them at risk for the development of cancer. While it is still believed that the risk of cancer in these individuals is small, it may be higher than in the general population." (Communication, Paul Cheney, M.D. 2/12/88)

"There is no firm evidence that EBV is the major cause of the chronic mononucleosis syndrome. A great deal of research is currently being directed toward identifying its true cause(s) so that specific informatory tests can be developed. Meanwhile, no diagnostic tests are available that can differentiate persons with this syndrome from persons who have other illnesses or from persons who are not ill." (Communication, Sen. Ted Stevens from Dr. James Mason, Director, CDC. 5/14/87)

"Significant advances are being made in the basic virology of EBV and other human herpesviruses which are likely to be highly relevant to our understanding of the role these viruses play in Chronic Fatigue Syndrome." (Communication, Ann Schluederberg, Sc.D., Virology Program Officer, NIH, 7/9/87)

Recent research shows certain immune system cells called natural killer cells (NK cells) may have a marked depletion in people with CFS. The NK cells kill cells infected with viruses. The work on NK cells is still preliminary.

In a Redbook story, April 1988, "Newest Mystery Illness: Chronic Fatigue Syndrome", Gary Holmes, M.D., medical epidemiologist, Division of Viral Diseases, CDC, was quoted, "...It is a definite syndrome." In the same article, James F. Jones, M.D., a pioneer in CFS research, was quoted, "...We don't know what causes it--though in some cases the Epstein-Barr virus plays a key role--and we don't know why some people get it and why some don't..."

A variety of drug therapies are being used to treat CFS. More research can be directed to the studies of drugs which show promise in the treatment or control of symptoms and pain related to this disease.

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

At a recent House of Representatives Hearing, Dr. Anthony Fauci of the National Institute of Allergy and Infectious Diseases (NIAID) stated that they are spending $4 to $5 million of research money per year on this disease. (However, much of this funding appears to be for Epstein-Barr virus research and not for the chronic illness.) Dr. Fauci commented that in the absence of a break-through, they do not know how to proceed. Dr. Fauci's remarks should be an important reason to direct more funding to qualified outside researchers studying CFS. The research horizon should be expanded through the NIH Small Grants and through the conventional grant program to make more funding available for CFS research by those who have been pioneering and productive researchers on CFS.

We recommend that this disease be classified as a 'Priority Disease' to help expedite the granting of funds for research. We also recommend that more money be spent on CFS studies.

Dr. Nabih Abdou, Univ. of Kansas Medical Center, stated, "Until now most of the CFS patient treatment and counselling has been on an individual basis. At the University we are participating in a group of five medical centers to study CFS and to exchange and compare patient data. Now that something is known about how the disease affects people, it is time to establish a Multi-Center for diagnostics and treatment of CFS patients and to do extensive study on this disease."

Physicians who are researching CFS and/or treating patients strongly recommend the use of one or more certified laboratories for serological testing to standardize test procedures and create a 'clearing house' for collection and exchange of critical data on this disease.

CENTERS FOR DISEASE CONTROL (CDC)

According to researchers at the CDC, there is no known diagnostic laboratory test or pathognomonic clinical findings for CFS; it remains a diagnosis of exclusion. Because initial studies conducted by the Div. of Viral Diseases suggest the physicians frequently misdiagnose other conditions as the CFS Syndrome, the CDC surveillance (which may operate for 3-1/2 years) and studies of CFS will require the commitment of trained medical personnel to educate physicians about the diagnosis of this illness and to confirm reported suspected cases with reviews of medical records and interviews of patients themselves. To accomplish this, the CDC has issued a request for a contract to establish the surveillance systems in 2 sentinel counties and in part of metropolitan Atlanta.

The surveillance system will probably provide a group of patients who would be excellent for study to characterize the immunological status of patients and to determine the etiologic agent(s) and cause(s) of the disease.

The CDC researchers indicate that although several human viral pathogens (including Epstein-Barr virus, human herpesvirus-6, adenovirus and enteroviruses) have been postulated to cause CFS, definitive evidence indicating etiology has not been developed for any of these agents. It has been suggested that since persistent herpes and enterovirus infections appear to be the most likely agents, additional virologists should be added in each of these areas for studies of etiology in addition to an immunologist. This will require 6 full time equivalents (FTEs) and $300,000 in laboratory equipment.

Funds will be needed for 3-1/2 years for the present active surveillance at an average annual cost of $245,000. Additional funds will be needed to expand the program: (1) to add two more sentinel counties at a cost of $200,000 per year total; (2) to enroll patients identified outside of Atlanta in the case-control etiologic studies; (3) $200,000 a year to pay for the time of local investigators, travel and for specimen shipping costs. The needs of the CDC program will be $945,000 and the addition of 6 FTEs.

"There is no consensus in the medical community over the cause of this lingering illness, or even whether it is really an organic disease. But more and more physicians are recognizing this as a serious health problem in need of research and understanding." (Congressman Henry A. Waxman, Chairman, Subcommittee on Health and the Environment, Hearing 3/4/88)

An important research paper is expected to appear soon in a prestigious medical journal detailing the findings of research studies of this disease. Indications are that this report will present a breakthrough in the understanding of the disease as well as important information in understanding the cause(s) and means of transmittal. These studies with a large number of patients have resulted from research funded by private and foundation contributions. This type of research that could be aided by the NIH Small Grants Program as well as the use of the conventional NIH grants program for more exhaustive studies.

We urge this Committee to recommend:

(1) That the National Institute of Allergy and Infectious Diseases (NIAID) expand its research on Chronic Fatigue Syndrome in the search for a proven diagnostic method, means of treatment and, hopefully, a cure. A minimum of $5,000,000 should be funded for research on this syndrome which has become a serious national health problem.

(2) That the National Institutes of Health declare Chronic Fatigue Syndrome as a 'Priority Disease'.

(3) That the NIAID make effective use of the existing Small Grants Fund and expedite the issuance of these grants to recognized CFS researchers. $500,000 should be made available for these Small Grants.

(4) That the Centers for Disease Control be funded to continue the development and implementation of the Chronic Fatigue Syndrome surveillance and long term follow up systems and to develop and conduct case-control, etiologic and risk factor studies. $945,000 should be appropriated to expand the surveillance network, for laboratory equipment, and for the patient studies. Six full time equivalents should be added to accomplish this work.

On behalf of the dedicated CFS researchers, the many patients and their families, we thank the Committee for its attention to this national health problem and ask that the Committee continue in its efforts so that research will lead to answers about this debilitating syndrome which affects the lives of so many Americans.

STATEMENT OF THE AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

I am Thomas Dameron, Jr., M.D., President of the American Academy of Orthopaedic Surgeons. I am also in the private practice of orthopaedic surgery, and a clinical professor in the Division of Orthopaedic Surgery at the University of North Carolina.

I am pleased to appear before you today to present the Academy's position on the need for continued and, if possible, expanded funding of research on the musculoskeletal system, at the National Institute of Arthritis, Musculoskeletal, and Skin Diseases.

The musculoskeletal system encompasses the:

(1) bones;
(2) joints;
(3) muscles and the nerves that control them;
(4) tendons; and
(5) ligaments that enable each of us to perform the tasks of every day living.

As I am sure you are aware, Mr. Chairman, diseases of the musculoskeletal system rank among the most common causes of pain, and disability. In addition to the toll they exact in human suffering, the economic impact of these disorders exceeds $65 billion annually, when measured in terms of the added costs of medical care and lost productivity.1/

Mr. Chairman, on an annual basis more than 40 million people suffer from bone and joint disorders, fractures, and injuries of the tendons and ligaments; approximately 31 million Americans suffer from arthritis, a disease that encompasses more than 100 different disorders of the joints and connective tissues, including osteoarthritis, rheumatoid arthritis, systemic lupus erythematosus, gout, and ankylosing spondylitis, or

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1/ The Frequency of Occurrence, Impact, and Cost of Musculoskeletal Conditions in the United States. Troy L. Holbrook.

what is commonly known as spinal arthritis, and numerous others are afflicted with bone cancer, cerebral palsy and osteoporsis.

Congress wisely recognized the severity and magnitude of these diseases when it created a separate National Institute of Arthritis, Musculoskeletal, and Skin Diseases. This new institute, with the help of this subcommittee, is beginning to provide for a highly focused research program. Although much has been learned about the symptoms and the progress of these diseases and disorders and their management, medical science has yet to discover cures for many of them.

Research Needs

The research opportunities in the Arthritis, Musculoskeletal and Skin Institute are as varied as the diseases it is attempting to learn about.

Orthopaedic research supported by the NIAMS includes:

- basic and clinical studies of normal bone, bone growth, and bone metabolism;
- bone and joint diseases, injury, and repair;
- therapies such as joint replacement, and bone and cartilage transplantation to treat these disorders.

Osteoarthritis, the most common form of arthritis, afflicts 16 million Americans, and remains a leading cause of pain and disability. The disease mainly affects the cartilage of the joint causing it to fray, crack, ulcerate, and erode, resulting in an uncushioned bone-on-bone joint.

Research indicates that osteoarthritis may not necessarily be a wear-and-tear disease nor an inevitable consequence of aging. There appears to be important chemical differences between osteoarthritic cartilage and aging cartilage.

The proceedings of a major scientific workshop on causative mechanisms of osteoarthritis were published last year. The report delineates over 130 specific recommendations for osteoarthritis research, and provides a course for future research on osteoarthritis. I am proud that the American Academy of Orthopaedic Surgeons cosponsored this workshop with the National Institutes of Health and we urge this subcommittee to provide adequate funding to carry out the workshop recommendations.

Bone Research. Research advances have also been made in understanding bone cell regulatory factors, and support for this work, along with initial studies in clinical application of these new developments, should go forward. The continuous remodeling of bone is a complex, multifactorial process. Several controlling proteins recently have been identified and isolated. These new leads should be pursued.

Recently a significant finding was published indicating that the use of estrogen by postmenopausal women protects them against subsequent hip fracture. It was recommended by the scientist that women seriously consider, with their physician's advice, taking estrogen hormones immediately following menopause in order to delay the onset of osteoporosis. Women are more frequently affected than men. About 1.3 million fractures attributable to osteoporosis occur each year. This number includes approximately 210,000 hip fractures suffered by the elderly each year. Even a small reduction in the number of hip fractures could save much suffering and thousands of lives and many hundreds of millions of dollars of federal funding used to care for the elderly injured each year.

Also, the discovery and isolation of new substances that spur bone growth of existing bone and induce new bone formation are raising the possibility of remeding bone defects caused by injury and disease.

Specialized Centers of Research

Mr. Chairman, I want to express the gratitude of the Academy to this Committee for including funds in the 1987 Appropriations for nine Specialized Centers of Research. These centers provide a highly effective means of concentrating basic and clinical research efforts on high priority diseases such as osteoarthritis, rheumatoid arthritis, and osteoporosis. Through this mechanism one can expect to see rapid translations of advances in the basic sciences into clinical application.

There is great enthusiasm in the musculoskeletal research community for the Centers, and again we thank you for your confidence and support.

Mr. Chairman, basic and clinical research remains the lifeline of improved patient care. Each new bit of information, added to the previously existing scientific data base, contributes to clinical advances and the alleviation of human suffering.

Before the 1970's about 80 percent of the patients with malignant osteosarcoma died within two years of diagnosis. Today, nearly 80 percent survive.

Mr. Chairman, until recently, bone cancer of the arm was almost always treated by amputating the limb. Today, because of reconstructive surgery, biomechanics, bone imaging, and chemotherapy, many bone tumors can be treated in a way that spares the limb. For a bone cancer patient facing the loss of an arm or leg, surgery that spares the limb can be a godsend. But it's not without risk and this technique should only be used on carefully selected patients. Therefore, research in areas such as this must be continued in order to provide those afflicted with not only longer, but better lives.

Treatment of musculoskeletal diseases has dramatically changed over the past 15 years, as a result of improved knowledge of the basic nature, causes and natural history of the disease processes. New technology involving diagnostic and treatment modalities has greatly improved the results in people suffering from afflictions of the musculoskeletal system.

Mr. Chairman, the President's budget for 1989 does not meet the needs of biomedical research. The efforts of this committee to maintain the momentum in science and its attempts to bring hope to those individuals suffering from disease are severely cut short in the 1989 budget.

While we fully appreciate the difficult fiscal conditions under which you are operating, we believe, like Emerson, that "Health is the first wealth," and thus the government must provide for the sound health of its citizens today and into the future.

With this in mind, we respectfully urge this committee to provide $224 million for the National Institute of Arthritis, Musculoskeletal, and Skin Diseases.

On behalf of the over 12,000 members of the American Academy of Orthopaedic Surgeons, thank you for your past support and for giving me this opportunity to testify before you today.

I will be happy to answer any questions.

STATEMENT OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION

My name is Edward Truschke and I am President of the Alzheimer's Disease and Related Disorders Association.

By way of background, Mr. Chairman, our Association was established in 1979 by the families and loved ones of Alzheimer patients. Since that time, the organization has grown from a handful of family care givers into a network of more than 170 chapters and over 1,000 family support groups nationwide. I should point out, however, that throughout this period of tremendous growth, our mission has remained clear and constant: To help find a cure, while easing the burden of those unfortunate families struggling to cope with Alzheimer's Disease and related disorders.

If I may, Mr. Chairman, I would like to take this opportunity to thank you and the members of this Subcommittee for your leadership and foresight in this area. Among other things, your concern and support have gone a long way towards raising the general level of awareness and understanding about this dreadful disease. More than that, the funds you have provided in the past have already begun to generate new and promising leads.

Mr. Chairman, more than 2.5 million Americans now suffer from Alzheimer's Disease, a degenerative brain disorder that eventually robs its victims of their capacity to function as productive individuals. While the first signs of the disease are usually limited to the loss of recent memory, Alzheimer's Disease progresses to the point where its victim can no longer think clearly, communicate, or carry out even the most basic activities of daily living without constant help and supervision from others.

We still do not know what causes Alzheimer's Disease but as I mentioned, with this Subcommittee's help, scientists have begun to unravel some of the mysteries surrounding it.

Last year, for example, researchers were able to identify a genetic marker linked to Alzheimer's Disease, the first solid evidence that at least one form of the disease is inherited. Scientists have also found that people with Alzheimer's Disease have abnormal numbers of the gene responsible for producing a brain-crippling protein associated with the disease.

Clearly, these and other findings have opened an exciting new chapter in research. More importantly, they bring us another step closer to our goal of finding a cure or a way to prevent this disease.

Be that as it may, we still face the very real threat that Alzheimer's Disease will bankrupt society -- physically, emotionally, and financially.

We estimate that the cost of caring for Alzheimer victims costs as much as $48 billion annually; recently Dr. Franklin Williams testified to this Subcommittee that the total societal costs run as high as $80 billion each year.

More troubling still are the demographic projections for the next several years, when we can expect to see a tremendous increase in the age groups most at risk. According to the Office of Technology Assessment, well over 7 million Americans may suffer from Alzheimer's Disease and related disorders by 2040 -- five times as many as today.

For our part, the Association has mounted its own research program with the help of private donations. By the end of 1987, we had awarded more than 170 research grants, totaling over $7.2 million. By the end of this year, we expect to award another 57 research grants. But our experience has underscored the fact that scientific interest far exceeds the resources available. In fact, not unlike the National Institutes of Health, we turn away 80 percent of the proposals we receive.

Mr. Chairman, current federal spending for research on Alzheimer's Disease is about $90 million. That amounts to an investment of about $36 per victim, as compared to an average $12,000 annually to care for a person at home or $23,000 for nursing home care.

We must begin to close that gap.

At the same time, we must not overlook the present-day needs of patients and their families.

About 70 percent of the victims of Alzheimer's Disease are being cared for by their families and close friends. They do this at great physical, emotional, and financial cost to themselves -- with little help from government or other sources. For the most part, families find that the services they need, such as respite care, in-home health care, and adult day care, are not accessible, that local programs will not accept people with dementia, and that professional care givers are not trained in the special care needs of these patients.

Add to that the fact that neither Medicare nor most private insurance plans will cover the cost of caring for an Alzheimer victim and you have perhaps the most compelling case for a system of long-term care in this country.

Recommendations

While Congress debates the broader issue of long-term care, we urge this Subcommittee to continue its long-standing leadership role by taking the following steps.

- Expand the federal investment in medical research to at least $175 million and strengthen the capacity of the Alzheimer's Disease Research Centers to fulfill their mission to not only conduct research, but also to train health professionals and serve as a link between the research community and the public.

- Provide $8 million to support research aimed at improving the organization, delivery, and financing of desperately-needed services for our families.

- Continue to support funding for the Alzheimer's Disease Education Center, as well as the National Advisory Panel for Alzheimer's Disease.

Thank you, Mr. Chairman. I would be glad to answer any questions you may have.

STATEMENT OF THE NATIONAL LOW INCOME ENERGY CONSORTIUM

ON BEHALF OF THE MARYLAND DEPARTMENT OF HUMAN RESOURCES, COMMUNITY SERVICES ADMINISTRATION, MARYLAND ENERGY ASSISTANCE PROGRAM AND THE NATIONAL LOW INCOME ENERGY CONSORTIUM, I WOULD LIKE TO THANK YOU FOR GIVING ME THE OPPORTUNITY TO PROVIDE TESTIMONY ON THE LOW INCOME HOME ENERGY ASSISTANCE BLOCK GRANT.

I THINK IT IS UNCONSCIONABLE THAT THE ADMINISTRATION IS CONSIDERING A 21% CUT TO LIHEAP IN FY '89, ON TOP OF THE 16% CUT EXPERIENCED IN FY '88. THE ADMINISTRATION MUST BE FORCED TO RECOGNIZE THAT ENERGY SERVICE IS ESSENTIAL TO MANY FAMILIES AND INDIVIDUALS. WITHOUT ENERGY ASSISTANCE BENEFITS, MANY OF THE POOREST OF THE POOR, PARTICULARLY OUR YOUNG CHILDREN, FRAIL ELDERLY AND HANDICAPPED, WOULD HAVE TO MAKE A CHOICE BETWEEN RENT, FOOD OR UTILITY SERVICE. IT IS AN UNTENABLE SITUATION FOR ANY FAMILY.

IT IS MY CONTENTION THAT A NATIONAL ENERGY POLICY MUST EXPLICITLY RECOGNIZE THE SPECIAL NEEDS OF LOW INCOME AND FIXED INCOME FAMILIES AND COMMIT TO PROVIDING ONGOING FEDERAL FUNDS TO THE LOW INCOME ENERGY ASSISTANCE AND WEATHERIZATION ASSISTANCE PROGRAMS. IT IS UNREALISTIC TO THINK THAT OIL OVERCHARGE MONIES WILL COVER THE SHORTFALL OR THAT PUBLIC/PRIVATE PARTNERSHIPS CAN SOLVE THE PROBLEM. THERE MUST BE A NATIONAL COMMITMENT!

FORTUNATELY, THIS YEAR, MARYLAND'S ENERGY OVERCHARGE RESTITUTION TRUST FUND BOARD HELD THE MARYLAND ENERGY ASSISTANCE PROGRAM HARMLESS FROM THE $4.7 MILLION IN FEDERAL CUTS. HOWEVER, IT IS VERY UNLIKELY THAT THE BOARD WOULD BE ABLE TO PROVIDE ADDITIONAL FUNDS SHOULD LIHEAP BE CUT AGAIN. MOREOVER, THE OPPORTUNITY TO UTILIZE UNALLOCATED OIL OVERCHARGE MONIES IS WANING. WE CURRENTLY HAVE ONLY 2 MILLION DOLLARS. THE DAYS OF SMOKE AND MIRRORS ARE OVER - STATES NEED A FEDERAL COMMITMENT TO LIHEAP.

WITH THE EXPECTATION OF FEWER DOLLARS, MEAP HAS THREE OPTIONS; (A) REDUCE BENEFIT AMOUNTS AND CONTINUE TO SERVE THE CURRENT CLIENT BASE OF 86,500 HOUSEHOLDS; (B) MAINTAIN CURRENT

BENEFIT LEVELS AND REDUCE THE NUMBER OF LOW INCOME FAMILIES SERVED; OR (C) A COMBINATION THEREOF. BY MAINTAINING THE CURRENT BENEFIT LEVELS APPROXIMATELY 24,770 FEWER LOW INCOME FAMILIES WOULD BE SERVED BASED ON THE ADMINISTRATION'S BUDGET REQUEST. REGARDLESS OF ANY OF THE ABOVE ALTERNATIVES, MANY FAMILIES WILL BECOME ELIGIBLE FOR STATE FUNDED EMERGENCY AID AND/OR DRAIN THE RESOURCES OF PRIVATE FUEL FUNDS AND OTHER NONPROFIT AGENCIES. MANY FAMILIES WILL ACCRUE UTILITY ARREARAGES OR FUEL BILL BALANCES WHICH WILL MAKE THEM VULNERABLE TO LOSS OF HEAT, DISCONNECTION OF UTILITY SERVICES AND/OR THE EFFECTS OF COLD AND FREEZING CONDITIONS. FEWER FAMILIES WOULD BE ELIGIBLE FOR THE PUBLIC SERVICE COMMISSION'S UTILITY SERVICES PROTECTION PROGRAM WHICH HAS AS A PREREQUISITE PARTICIPATION IN MEAP. A FUNDING CUT WILL ADVERSELY AFFECT THE TRANSFER OF FUNDS TO THE MARYLAND DEPARTMENT OF HOUSING AND COMMUNITY DEVELOPMENT'S WEATHERIZATION ASSISTANCE PROGRAM, WHICH MAKES A SOUND INVESTMENT OF FEDERAL DOLLARS. CONCOMITANTLY, A REDUCTION WILL ALSO SIGNIFICANTLY LOWER THE FUNDS AVAILABLE FOR PROGRAM ADMINISTRATION AT THE STATE AND LOCAL LEVEL. THIS ADMINISTRATIVE FUNDING REDUCTION WOULD MOST CERTAINLY HAVE A NEGATIVE IMPACT ON OUR ABILITY TO SERVE CLIENTS. OUR STATE CANNOT ABSORB ANOTHER CUT.

LET ME MOVE NOW FROM A LOCAL PERSPECTIVE TO A NATIONAL ONE. AS I MENTIONED, I AM ALSO HERE TO TESTIFY IN MY CAPACITY AS CHAIR OF THE NATIONAL LOW INCOME ENERGY CONSORTIUM. WE REPRESENT A DIVERSE MEMBERSHIP OF ASSOCIATIONS, UTILITIES, OIL COMPANIES, STATE AND LOCAL ENERGY ASSISTANCE AND WEATHERIZATION PROGRAMS, REGULATORY AGENCIES AND NON-PROFIT ORGANIZATIONS. BECAUSE WE FACILITATE THE DIALOGUE BETWEEN SUPPLIERS, ON THE ONE HAND, AND LOW INCOME ADVOCATES, ON THE OTHER, WE ARE IN A UNIQUE POSITION TO IDENTIFY PROBLEMS AND BROKER SOLUTIONS. WE WORK TOGETHER TO ESTABLISH A BROAD-BASED FRAMEWORK FOR NATIONAL CONSENSUS BUILDING ON LOW INCOME ENERGY-RELATED PUBLIC POLICY ISSUES. WE ALSO EXPLORE AND PROMOTE SUCCESSFUL INNOVATIONS IN THE FIELD OF SERVICING LOW INCOME ENERGY CONSUMERS.

IN PREPARING FOR OUR ANNUAL CONFERENCE IN JUNE, THE CONSORTIUM COMMISSIONED A NATIONAL POLL TO EXPLORE THE CURRENT IMPACT OF ENERGY COSTS ON LOW INCOME PEOPLE. THIS PHONE SURVEY, CONDUCTED MID FEBRUARY 1988, REFLECTS A TYPICAL CROSS-SECTION OF AMERICAN CITIZENS. I WANT TO SHARE WITH YOU THE FINDINGS FROM THE POLL, AS I FEEL THEY BEAR DIRECTLY UPON THIS DISCUSSION.

- FIRST, ONE OF EVERY TWO AMERICANS HAD TO CLOSE OFF ROOMS OR TURN THE HEATING DOWN TO LOW LEVELS THIS PAST WINTER IN ORDER TO AVOID A HEATING BILL THEY COULD NOT AFFORD.
- POORER AMERICANS ARE COLDER THAN THE REST OF US. NEARLY TWO THIRDS OF THOSE WITH ANNUAL INCOMES OF $10,000 OR LESS HAD TO TURN DOWN THE HEAT
- THE FRAIL ELDERLY AND OTHERS IN POOR HEALTH ARE ALSO OUT IN THE COLD. OF THOSE HOMES CONTAINING FRAIL OR ILL FAMILY MEMBERS, OVER HALF WERE STILL FORCED TO TURN DOWN THE HEAT.

FINALLY, THOSE ELECTED OFFICIALS WHO THINK THE ENERGY CRISIS HAS GONE AWAY ARE IN FOR A BIG SURPRISE AT THE BALLOT BOX. THREE OUT OF FOUR AMERICANS SAY THAT A PRESIDENTIAL CANDIDATE'S ATTITUDES TOWARD THE NEED FOR HOME HEATING ASSISTANCE IS AN IMPORTANT REASON TO DECIDE FOR WHOM TO VOTE. AND TWO OUT OF THREE BELIEVE THE GOVERNMENT SHOULD PROVIDE HOME HEATING ASSISTANCE TO THOSE WHO CANNOT OTHERWISE AFFORD IT. I MIGHT ADD THAT THIS SUPPORT IS ACROSS THE BOARD --- MAJORITIES OF EVERY DEMOGRAPHIC SUB-GROUP AGREED THAT HOME HEATING ASSISTANCE IS THE RESPONSIBILITY OF GOVERNMENT.

WHILE THIS DATA SUGGESTS THAT ENERGY COSTS REMAIN ON THE MINDS OF ALL AMERICANS, THE ENERGY CRISIS IS A DAILY CONCERN FOR POOR AMERICANS. IN 1984-85, ALMOST ONE-FOURTH OF POVERTY OR NEAR POVERTY HOUSEHOLDS SPENT MORE THAN TWENTY-FIVE PERCENT OF THEIR INCOME ON COMBINED RESIDENTIAL FUEL EXPENDITURES. VIRTUALLY NO HOUSEHOLDS IN ANY OTHER INCOME CATEGORY SPENT COMPARABLE PROPORTIONS OF THEIR INCOME ON ENERGY.

THE CONSEQUENCES OF SUCH ECONOMIC BURDENS UPON THOSE LEAST LIKELY TO AFFORD ENERGY COSTS ARE OBVIOUS. FIRST OF ALL, IT BECOMES ECONOMICALLY DIFFICULT, IF NOT IMPOSSIBLE, FOR MANY TO PAY UTILITY BILLS. BETWEEN OCTOBER 1981 AND APRIL 1982, APPROXIMATELY ONE MILLION POVERTY OR NEAR POVERTY HOUSEHOLDS WERE UNABLE TO PAY FOR FUEL OR UTILITIES AND SUFFERED A RESULTING LOSS OF HEAT FOR ONE OR MORE DAYS. THOSE WITH MINIMAL OR FIXED INCOMES THAT DO PAY ARE OFTEN LEFT WITH MEAGER RESOURCES FOR OTHER VITAL NECESSITIES.

NEARLY A QUARTER OF ALL ELDERLY AMERICAN HOUSEHOLDS HAVE INCOME AT OR BELOW 125 PERCENT OF THE POVERTY LEVEL. SOME 5.8 MILLION ELDERLY HOUSEHOLDS HAVE AVERAGE ANNUAL INCOMES OF ONLY ABOUT $5,300. WHEN THE COST OF HOUSING, FOOD, AND HOME ENERGY ARE DEDUCTED, THE AVERAGE LOW INCOME ELDERLY HOUSEHOLD HAS LESS THAN $500 LEFT IN DISCRETIONARY INCOME WHICH REPRESENTS $9.61 PER WEEK TO BE EXACT.

WHEN POOR PEOPLE ARE CONFRONTED WITH SITUATIONS LIKE THIS, THEY FALL INTO A VICIOUS CIRCLE. SHUT-OFFS, EVICTIONS, FAMILY DISRUPTIONS AND HOMELESSNESS LOOM LARGE AS POSSIBILITIES. WHAT COULD HAVE BEEN PREVENTED BY A HOME HEATING SUPPLEMENT SOON REQUIRES THE WELFARE HOTEL. AND THE POOR FAMILIES THAT COULD HAVE BEEN CLIENTS ONLY OF GOVERNMENT ASSISTED HEATING PROGRAMS NOW BECOME CLIENTS OF STATE SOCIAL SERVICE AGENCIES, AT MANY TIMES THE ORIGINAL COST.

IF YOUR CONCERN IS TO DETERMINE WHETHER THE POOR CONTINUE TO SUFFER FROM HIGH ENERGY COSTS, I HOPE YOU WILL AGREE THAT THE ANSWER IS AN UNQUESTIONABLE YES. AND IF YOU WERE TO DELIBERATE WHETHER IT IS GOVERNMENT'S RESPONSIBILITY TO ALLEVIATE THIS SUFFERING, I HOPE THE FACT THAT THE MAJORITY OF THE AMERICAN PUBLIC SUPPORTS HOME HEATING ASSISTANCE FOR THE POOR WILL CONVINCE YOU TO ACT FAVORABLY ON OUR REQUEST.

STATEMENT OF THE COLUMBIA GAS DISTRIBUTION COMPANIES

I appreciate the opportunity to provide a written statement for the record in support of adequate funding for the Low-Income Home Energy Assistance Program (LIHEAP).

Columbia Gas Distribution Companies consists of Columbia Gas of Kentucky, Columbia Gas of Maryland, Columbia Gas of New York, Columbia Gas of Ohio, Columbia Gas of Pennsylvania and Columbia Gas of Virginia. Collectively, these Columbia companies provide natural gas service to more than 1.6 million consumers.

We are deeply committed to meeting the energy needs of all of our consumers, including our low-income consumers. To this end, we have long supported federal energy assistance programs such as LIHEAP and the Department of Energy weatherization program. In addition to supporting federal funding efforts, we at Columbia have developed several innovative and effective programs in this area.

We have supported and developed programs to aid low-income consumers because we believe the burden of the low-income consumers' needs does not rest solely on the shoulders of the federal government. Rather, the states and the private sector also have a responsibility and do contribute significantly to the needs of low-income consumers.

COLUMBIA OFFERS PROGRAMS TO ASSIST LOW-INCOME CONSUMERS

For example, at Columbia we offer a fuel fund program in which our stockholders match from $1 to $2 for every $2 donated by our consumers. In the past five years, this program has generated $1.1 million in emergency assistance to low-income consumers in our service area.

Another program is our Columbia/Citizens Energy Program. We work closely with the not-for-profit Citizens Energy Corp. in implementing a fuel fund program that utilizes spot market priced natural gas supplies. This program has generated $6.1 million in energy assistance funds for Columbia's low-income consumers since 1982.

At Columbia Gas, we have also developed a customer relations program to provide assistance for our low-income consumers, not only in terms of their natural gas bills but in other areas as well. We have on our staff professional social workers to work with some of our low-income consumers who are attempting to become more self-sufficient.

Columbia is also actively supporting weatherization programs for the low-income household. We believe that weatherization represents the long-term solution for the energy cost situation that faces many low-income consumers.

LIHEAP FUNDING CUTS AFFECT ALL ENERGY CONSUMERS

The lack of adequate funding will affect more than the low-income households, because adequate funding of LIHEAP plays an important role in keeping utility rates stable for all consumers.

Low-income consumers who do not receive energy assistance, in many cases, simply cannot pay the full amount of their utility bills. With the mandated and voluntary moratoria on utility service terminations in most states during the winter months, these consumers continue to receive gas service. We attempt to work out a manageable plan for these consumers. However, if not successful, the cost of providing gas service without payment is ultimately considered part of a utility's costs of service and later becomes a burden that is borne by all utility consumers.

There are virtually millions of consumers who are on the fringe of LIHEAP eligibility. Often referred to as the "working poor," they are currently able to meet their energy costs without LIHEAP. However, an increase in energy costs could place these households in the same inability-to-pay situation that faces LIHEAP-eligible households today.

ADEQUATE FUNDING FOR LIHEAP

To millions of low-income consumers, LIHEAP is a badly needed safety net.

One of our customers who receives LIHEAP assistance demonstrates the need for LIHEAP.

She is single and is head of a household that includes two children, ages three and four. She also has responsibility for her 12-year-old sister since their mother, who was previously head of the household, passed away. This woman works part-time, earning about $400 a month and receives some welfare subsidies.

After paying her bills for food, rent and energy, she has about $12 a week left over for other expenses. Without the assistance she receives from LIHEAP even less money would be available to maintain her household.

Her situation is just one example of thousands of people who are trying very hard to make ends meet and LIHEAP is a great assistance to them.

STATE SUPPLEMENTS ARE ONLY TEMPORARY

Many states have supplemented their LIHEAP programs with oil overcharge monies in order to continue to help the maximum number of low-income consumers. However, Congress should note that the amount of oil overcharge funds is diminishing.

It is our understanding that, for the most part, states have already spent or allocated oil overcharge funds they have received. The timing and amount of state's future overcharge funds is very uncertain.

CONCLUSION

Certainly, both the private and public sector must be prudent managers of spending. However, assistance is needed for the low-income consumer who is struggling to make ends meet. There is a limit as to what assistance the state and local governments and businesses can provide in order to supplement the federal budget cuts of the LIHEAP program.

I respectfully urge the Subcommittee to support our recommendation to restore LIHEAP funding closer to the FY 1987 funding level.

STATEMENT OF THE RENAL PHYSICIANS ASSOCIATION

The Renal Physicians Association, (RPA) is an organization representing over 1,300 nephrologists nationwide, who participate in research and treatment of renal disease and related disorders, and are dedicated to ensuring optimal care for these patients. We are pleased to have the opportunity to express our support for increased funding for fiscal year 1989 for the National Institute of Diabetes and Digestive and Kidney Diseases. The broad mandate of the NIDDK encompasses some of the most debilitating and costly diseases affecting our nation's citizens.

Kidney and urinary tract diseases affect more than thirteen million Americans and account for over 80,000 deaths each year. Federal expenditures to treat patients with end-stage renal disease who require maintenance dialysis and kidney transplantation are approximately $3.0 billion annually. It is worth noting, however, that ascertaining the costs, incidence and problems related to the more common kidney diseases has been more difficult: In part, this is caused by the lack of epidemiological studies such as those done for other diseases, for example heart and lung diseases. Perhaps more important, the available data has been analyzed only in isolation, instead of as part of a larger picture. The end result is that the problems associated with kidney diseases are much more pervasive than previously acknowledged.[1]

Even against this backdrop, it is still abundantly clear that funding for research to address kidney diseases is extremely cost effective: last year, NIDDK's total budget ($530 million) amounted to less than one-sixth of the estimated costs of the ESRD program. Yet, through NIDDK research, exciting breakthroughs in understanding and treating kidney disease are being made; proof that sound federal commitment to research funding is a fiscally responsible choice -- one that will bear fruit in future years by reducing the costs of the ESRD program.

To understand and combat kidney disease, NIDDK grantees are actively exploring the normal structure and function of the kidney and selected genetic and acquired diseases of this organ. High priority areas of research include understanding immune-mediated diseases of the kidney; improving the success of kidney transplantation and the prevention of renal failure due to diabetes -- the single greatest cause of chronic kidney failure. NIDDK is also sponsoring efforts aimed at a better understanding of the disease processes in polycystic kidney disease, acute renal failure, and glomerulonephritis. An emerging area of interest is the relationship of kidney and urologic diseases to AIDS. This is the subject of a recent NIDDK program announcement.

End stage renal disease (ESRD) is the result of permanent damage to both kidneys -- the organs which filter waste from the blood, and monitor and control the amount of body fluids and electrolyte balance, preventing either fluid overload or "dehydration". The kidneys also produce and contribute to the action of several hormones. When the kidneys are not functioning, a patient develops uremia, a buildup of waste products in the blood which can cause permanent damage to numerous body systems and death. For this reason, patients with ESRD must undergo regular dialysis, a procedure which removes waste from the blood.

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[1] The statement of the Chairman of the National Kidney and Urologic Diseases Advisory Board before the House Appropriations subcommittee (May 3, 1988) concluded that "the true cost of kidney and urologic diseases far exceeds the $14 billion a year in direct medical costs that have been quoted in the past."

Approximately 99,000 patients with ESRD are on dialysis, and more than 9,000 received kidney transplants, according to most recent available data.[2/] NIDDK has initiated a Consolidated ESRD Data System in cooperation with the Health Care Financing Administration (HCFA) to meet the needs of the research community for better information on the ESRD patients across the country -- this the U.S. Renal Data System (US-RDS). RPA was very involved in getting the statutory language in place to establish the ESRD data registry (OBRA, 1986), and in the re-organization and redesignation of the ESRD networks -- organizations which characterize the ESRD patient population, describe the demographic variables and geographic distribution of patients across the different types of treatment, establish prevalence and incidence rates of the different types of kidney diseases that lead to ESRD, and assess the relative merits and medical efficacy of various current and newly developed treatment interventions for the ESRD patient population. This information is then sent on to the US-RDS. Research opportunities are also being identified, for example studies on the underlying causes of ESRD, and efforts which will focus on surveillance for malignancies. In addition, continuing improvement is taking place in the technology of dialysis delivery. Technological advances will contribute significantly to reduced morbidity of dialysis patients.

Kidney disease of diabetes mellitus (KDDM) is the single most common cause of end stage renal disease and one of the most serious complications of diabetes mellitus. Approximately one-fourth of new patients beginning maintenance dialysis have diabetes; diabetics on dialysis have a mortality rate between two and five times that of nondiabetics. In its FY 1988 report, the Senate Appropriations committee urged the NIDDK to undertake new kidney diabetes mellitus research initiatives. However no new money was provided for this in the Continuing Resolution for FY 1988. NIDDK has

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[2/] End Stage Renal Disease Patient Profile Table, 1986 ESRD Information Analysis Branch, DHHS Bureau of Data Management and Strategy.

recently issued a new program announcement for basic studies on diabetes and renal disease to accommodate from 10 to 15 awards for up to 5 years, contingent upon sufficient funding. We therefore urge that specific funding of $3.7 million for the diabetes initiative be included for FY 89.

The George O'Brien Kidney and Urological Research Centers Program was authorized by Congress in 1986, to encourage interdisciplinary research and support clinical and epidemiological studies of disorders of the kidney and urinary system. However, ever since its inception this program has not been fully funded. For FY 1989, we recommend an increase to full funding for the six existing centers, ($1 million per center). In addition, we believe that additional centers should be created in light of the excellent proposals which could not be funded in the past.

An area of increasing concern to RPA is research training. Individual and institutional training awards provide critical support to young investigators who choose careers in research and or teaching. Yet we are concerned that the importance of this area has not been fully perceived by Congress. In the absence of a strong research training program, our ability to draw young physicians into the laboratories will be severely compromised. RPA is also deeply concerned about support for NIDDK clinical trials. Adequate funding must be provided in order to effectively move kidney disease-related research from the laboratory bench to the hospital bedside.

Mr. Chairman, the NIDDK is the lead federal agency for research on prevention, early diagnosis and treatment of diseases of the kidney and urinary tract. Yet, there is reason for continued concern about the present funding situation for this important institute. For the current fiscal year, individual research grants are automatically cut by 10 percent, and support for centers is reduced by 15 percent. Particularly discouraging, the NIDDK is now able to fund only 26 percent of approved grants, corresponding to a cut-off priority score of 145. Substantial important research cannot be performed, as a result. Under the President's budget request, the situation would be little better: Though NIDDK predicts about 680 new and competing renewal grants will be funded in FY 1989 (an increase over the current fiscal year) the committee should remember that this is still fewer than the actual number in this category funded in FY 87 -- that is to say that this does not really represent an increase at all!

RPA believes that a less than adequate federal committment to biomedical research will result immediately in diminished ability to translate basic research into clinical advances; and, in the long-run, collapse of our basic science knowledge base which must continuously be replenished. The RPA has taken an active role in advancing this message — and especially the ramifications for kidney disease research -- through participation in the public hearings of the National Kidney and Urologic Diseases Advisory Board. We are gratified that the presentations to the Advisory Board will form the basis for the development of the first national long range plan to combat kidney and urologic diseases. We urge your committment to this important effort.

We hope that you will consider seriously the information we have provided. Our total funding recommendation for NIDDK for FY 89 is $680.5 million. This level (as well as our specific recommendations) are consistent with the determinations of the Inter-Society Council for Research of the Kidney and Urinary Tract, of which RPA is a member. In addition, RPA supports, along with numerous other professional organizations and voluntary health groups, overall funding for the National Institutes of Health of $8.2 billion for FY 89.

We urge you to take all necessary steps to ensure that funding levels of $680.5 million for NIDDK and $8.2 million for NIH, overall, are enacted for FY 89. The Renal Physicians Association would be happy to serve as a resource to the committee as determinations are made.

STATEMENT OF THE NEW HOPE PARENTS ASSOCIATION

Mr. Chairman, my name is Bowley N. Moore. I am the Eastern Region Director for the New Hope Parents Association (NHPA). The primary objectives of the NHPA and its affiliate, the New Hope Research Foundation, are to provide education on treatment and services in the United States and internationally, and to promote research serving the physically and mentally disabled. We are grateful for the opportunity to share our views concerning federal support through the National Institute of Child Health and Human Development (NICHD), for research on mental retardation and related disabilities.

We are aware that the NIH regards basic science research to be its primary mission. Clinical and applied research are supported but are secondary objectives. This orientation is evidenced by the NIH response to the AIDS epidemic. It was not until after the public outcry and demand for AIDS directed research that the NIH directed the power of basic research to clinical and applied research aimed at the prevention and treatment of AIDS. Congressional directives and allocation of funds played an important role in this shift in orientation by the NIH. Research targeted at resolving the AIDS problem has increased remarkably in response to these pressures from outside the NIH.

The AIDS epidemic is regarded as a crisis of national proportions. Today, there are an estimated 64 thousand AIDS victims. Projections indicate that there will be one million in the near future. We suggest that the over 6 million Americans afflicted with mental retardation constitute a crisis condition of equal importance and one deserving an adequate and targeted response from the NIH equal to that taken for AIDS research.

The NICHD, as an administrative entity of the NIH, emulates the orientation of its governing agency. Basic science research is stressed and is fostered by selection of scientific reviewers of grant applications identified with basic science research. Reviewer experience and identification with a given developmental disorder as mental retardation is secondary to basic science expertise in the selection of most reviewers. This approach has the support of the broad community of basic scientists and their parent universities who are favorably supported by the flow of federal funds for research and who have great strength in shaping national research priorities. Parent advocate groups for the mentally retarded, on the other hand, have a smaller voice in giving direction to our nation's research efforts. They are impelled toward greater concern for clinical and applied research which, when effectivly targeted, might more rapidly bring beneficial effects for their children. Their views need to be heard.

The NMPA and other parent advocate groups have deep appreciation for basic science research. Our concern, however, rests with efforts made to translate, quickly and effectively,emerging new research knowledge intoclinical and applied research which might bring beneficial effects to bear on the burden of mental retardation. It is in this sense that NIPA called for increased funding for the NICHD in testimony offered to the House Subcommittee on Labor, HHS, and Education. We do not believe, however, that increased funding alone will deliver the results we desire. Equally important, we believe, is how additional funds will be utilized and directed by the NICHD. On this matter we have strong reservations. Our concerns embrace the NICHD mental retardation research program as a whole, the performance of the MRRCs, and the Institute's Intramural Research Program.

The NICHD Mental Retardation Research Program

Research progress leading to the resolution of the problem of mental retardation is painfully slow. Hope for accelerated research advances was kindled in 1962 when Congress created the NICHD- a new institute with major responsibility for mental retardation research. Further encouragement was found in congressional action, taken in 1963, to appropriate funds for the construction of "Centers for Research on Mental Retardation and Related Aspects of Human Development" (MRRCs). A decade of accelerated and expanded mental retardation research followed until 1974 when change occurred in the administrative leadership of the NICHD. From that time funding for mental retardation research grants and contracts and in MRRC core support has declined steadily relative to other NICHD programs. A parallel decline has also occurred in the mental retardation research activities conducted by the Institute's Intramural Research Program. This pattern has serious implications for the future of mental retardation research.

The Mental Retardation and Developmental Disabilities Branch (MRDDB) of the NICHD is the Institute's primary administrative arm for guiding and funding its extramural program of mental retardation research. Grant applications submitted to the NIH are assigned to the MRDDB when the thrust of the applications are clearly shown to be directed at the problem of mental retardation. In FY 1987 the MRDDB funded approximately $4[illegible] million in research grants and contracts. This outlay, while large, is dwarfed by the magnitude of the research problems presented by mental retardation. Evenly distributed between each of the over [illegible] syndromes associated with mental retardation, this amount would permit the award and funding of but one grant to each syndrome. And the research requirements of each are multiple including such aspects as prevention; amelioration across numerous dimensions as health, speech and hearing, cognitive attributes, and education among others; and studies at all age levels from conception to old age. In view of these considerations, our slow pace to resolve the problem of mental retardation for any one syndrome is, in part, understandable.

To meet these challenges, the NICHD needs strong leadership for its MRDDB. Currently, its direction is provided on a part-time basis under an Interagency Personnel Agreement (IPA). IPAs are for a term of two years and are renewable. We feel, however, that mental retardation research demands full-time leadership of an enduring nature.

Mental Retardation Research Centers

When Congress acted, in 1963, to create Centers for Research on Mental Retardation and Related Aspects of Human Development (MRRCs), advocates for the mentally retarded shared the widely held view that Congress intended these centers to have a mission focal to mental retardation research. Over time, it appears that mental retardation research in the MRRCs has become less central and that increased emphasis is being given to the related aspects of human development. The permissive language in the Act providing for construction of the MRRCs gives justification to the universities having MRRCs for interpreting the scope of mental retardation research most broadly and for supporting research excursions across the broad field of human development that are remote from mental retardation. The result is further diminution of research focal to mental retardation.

The NICHD awards core grant support to the MRRCs to facilitate coordinated research activities. In FY 1987 approximately $6.7 million were allocated for core support for MRRCs. One center was awarded about $1.1 million in core support for that year even though it held no research grants and contracts from the MRDDB/NICHD. A similar pattern of minimal holdings in MRDDB, a branch clearly assigned to be the recipient of mental retardation research grant applications at NIH, is to be found in other MRRCs. This suggests that much of the research conducted by the MRRCs is not sufficiently related to mental retardation to warrant assignment to the MRDDB or, it is too basic to permit such identification. The merit of core support as a promoter of mental retardation research is open to question.

NICHD Intramural Research Program

Research emphasis on mental retardation research in the Intramural Research Program has shown a remarkable decrease. In its first decade, the NICHD supported 3 intramural branches (laboratories) whose work was directly related to mental retardation. Today, none are identified as having concern for mental retardation research. Review of the NIH Scientific Directory (1987) and Annual Bibliography (1986) shows that of 339 publications generated and reported by the Intramural Program for 1986 only one could be identified as directly concerned with mental retardation syndromes.The Director of the Intramural Program is an oncologist. It is not surprising that our review shows far more research on cancer conducted in the Intramural Program than for mental retardation.

Conclusion

NMPA recommends increased funding for NICHD sponsored mental retardation research. We do so with the hope that the Congress will consider our concerns for NICHD operationsand provide appropriate oversight.

STATEMENT OF THE GORGAS MEMORIAL INSTITUTE OF TROPICAL AND PREVENTIVE MEDICINE, INC.

Thank you for the opportunity to present this statement concerning the contribution of the United States to the Gorgas Memorial Institute (GMI) for the maintenance and operation of the Gorgas Memorial Laboratory (GML) in Panama. I am especially grateful for the chance to clarify some questions which you, Mr. Chairman, raised about GMI/GML during the hearings on NIH before this Subcommittee on 26 April, regarding the Fogarty International Center.

The annual contribution to Gorgas, as you know, is authorized by P.L. 70-350 as amended. At present, the authorization is $2,000,000 and the funds are now provided to Gorgas thru the Fogarty International Center of the NIH.

As I pointed out in a similar statement to this Subcommittee last year, the Republic of Panama also makes contributions to the Gorgas Memorial Laboratory operation. The sum of $10,000 is provided annually. This is not an insignificant amount when it is considered in the perspective of the relative populations and gross national products of Panama and the United States. This year, we cannot anticipate receiving the complete amount because of the political and economic disturbances. However, the other forms of Panamanian support to the Laboratory do continue, such as customs and tax exemptions, and the provision of physicians and technical personnel paid by the Health Ministry and assigned to GML projects. This support is not inconsiderable.

It is five years, now, since the Gorgas Memorial Laboratory was rescued from certain demise by the action of the appropriations committees of the Congress, after GMI/GML was included in a proposal by NIH to eliminate various types of center grants. (The inclusion of GMI/GML with NIH center grants was inappropriate, because the legislative authorizations are completely different.) This Subcommittee, then chaired by Senator Weicker, requested studies by the General Accounting Office and by the Office of Technology Assessment, to serve as bases for a decision on continued congressional contributions for GMI/GML. The reports of these studies, while recording various deficiencies that needed correction or improvement, recommended that GMI/GML be provided with funds for their continued existence. GMI was directed by the Senate report, No. 98-247, to respond to the criticisms expressed by GAO and OTA. There followed two letters which I addressed to Senator Weicker on 27 January 1984 and 15 March 1984, outlining actions taken and planned by GMI. I have copies of this correspondence to supply for the record or to be cited in the record.

The gist of the questions you addressed to Dr. Kupfer on 26 April related to peer review and oversight of the activities of GMI/GML. You also asked for details of funding of individual projects. I believe it is worthwhile now to give you an outline of changes and improvements that have occurred in our operations since the responses to criticism cited above.

In order to implement the recommendations that there be more formal and effective peer review mechanisms, GMI has used its Advisory Scientific Board (ASB), consisting of 36 scientists many of whom also serve on NIH review panels and/or advisory councils, and other consultants in the following ways:

1. In November 1984 and August 1985, Fogarty sponsored and participated in site visits to the GML to examine the programs in parasitology and in virology and epidemiology. Shortly after the second site visit, GMI called a meeting of its Advisory Scientific Board members in the related fields of interest. The meeting was held in Washington, D.C. with participation of Fogarty personnel, and the site visit reports served as the bases for the discussions. An attempt was made to come to a better definition of the role of small out-lying laboratories such as GML, as to the extent to which their special opportunities for field work can be exploited more with the adaptation of new sophisticated biotechnological procedures. Other important discussion items included the mechanisms for keeping the ASB members apprised of GML programs and utilizing their expertise in technical reviews of projects.

2. We have adopted the procedure of having scientific papers, in draft form, submitted by GML staff to GMI, for distribution to at least two reviewers on GMI's Advisory Scientific Board prior to submission in final form to a journal for publication. This procedure serves several purposes: a) It involves the ASB members in review not only of projects but of programs; b) it provides a way for the ASB members to participate in evaluation of the GML work and product; c) it ensures high quality in the papers that GML does send for publication; and d) it provides an opportunity for ASB members to offer suggestions for future work.

3. A new Director of the Gorgas Memorial Laboratory was appointed on August 1, 1987. He is William C. Reeves, M.D., whose curriculum vitae is attached for the record. Dr. Reeves is a bilingual, productive investigator with administrative skills, who has served the Laboratory during the past 10 years as Chief of GML's Division of Epidemiology. He has personally competed successfully in seeking grants and contracts and is today the principal investigator of three important GML projects supported with such funds.

In the interim between Directors and under Acting Director Rolando Saenz, M.D., the GML scientific staff conducted an evaluation of those activities being supported by core funds. This led to the elimination of some costly and poorly productive projects. The current GML staff now participates regularly in the evaluation of projects, programs and budgets before they are submitted to GMI for review. Director Reeves has prepared a scientific staff evaluation program to which all scientific staff have subscribed; it calls for a routine annual evaluation by the Director and Division Chiefs to assure adequate orientation and performance, followed by a formal biennial review by the Director and outside reviewers to assess scientific competence and merit to GML, and to recommend (or not) continued tenure at GML or advances in pay status. Dr. Reeves also proposes to involve more ASB reviewers in examination of GML work by bringing GML staff to discuss programs at large meetings to be held in the United States.

Several months ago, I began to explore with FIC the suggestions of another GML review, either here or in Panama, but the changes in FIC leadership at that time made discussions impractical. I do want to emphasize, however, that GMI/GML is perfectly willing to have FIC participate in evaluating our programs; we believe that this is necessary if FIC is to present our budget requests to the Congress. We are ourselves, we believe, to be held responsible for developing our programs and executing them, but appraisals of our performance are helpful and welcome.

I hope that this explanation of peer review of GML may allay any disquietudes about a failure on our part to submit to criticism or to be insensitive to the need for change. As we now stand, the GML is trimmer than before, as the result of the scrutiny that we have given to projects. We have lost some personnel because of this, but we expect to be able to recruit new investigators, with competences to handle some problems at a more sophisticated level. To accomplish this, however, we need our financial base restored. This base is the annual contribution provided under P.L. 70-350 which has been eroded in the last two consecutive fiscal years by the Gramm-Rudman-Hollings reductions. Let me remind the Committee at this time that the Gorgas Memorial Laboratory is a free-standing laboratory. The total staff numbers 110 of whom 10-12 are "full-time-equivalent" scientists; the rest are technicians, maintenance and administrative personnel. Approximately 73% of the core budget covers administrative and service expenses, including fixed payroll costs. The service work consists of the continual surveillance of the occurrence of diseases such as drug-resistant malaria, yellow fever, and viral encephalitis. This ought to explain why a U.S. contribution to core support is necessary. We are almost a unique resource in the Caribbean area. The only other tropical disease laboratory in the region is the Pedro Kouri Laboratory in Cuba which is supported, at least in part, by funds provided by France. GML must make provision, when we hire U.S. scientists, for transportation costs and other expenses. Moreover, in consonance with the recommendations in the OTA and GAO reports, we have to provide our new personnel with new and expensive equipment.

We are, indeed, making use of new aspects of biotechnology. For example, the only way to identify human papillomavirus types is by the use of DNA probes, because the virus has not been cultivated yet. We do this work at GML. We are seeking private donations to support the acquisition of new equipment and the refurbishing of our laboratories in order to support this new technology. We have been advised by a fund-raising consultant that we have little chance of obtaining sustaining endowments because exotic diseases attract little interest here, but that we might be more successful on a project, or instrument, basis. We have just received our first contribution in recent years from a private Panamanian source: $20,000 from the husband of the late Elena Maduro de Fidanque, for studies in clinical disease. We are working to get similar contributions from U.S. donors.

There are additional changes we have made in our organization and activities, which may be found in the annual report submitted to the Congress in April of this year. After a 3-year trial, we have given up the services of a paid Chief Executive Officer/President. I am serving pro bono in that capacity as well as Chairman of the Board. All of the Board members also serve without compensation. The Gorgas Memorial Institute is dedicated to maintaining the GML as a center of competence in tropical medicine within the Central American region. To this end, we request that the GMI/GML be supported through the Fogarty International Center in F.Y. 1989 at the level of $2,000,000 as authorized by P.L. 70-350 as amended.

Thank you very much, Mr. Chairman.

STATEMENT OF HON. JOHN HEINZ, U.S. SENATOR FROM PENNSYLVANIA

Good morning, Mr. Chairman. I appreciate the opportunity to testify on the Low Income Home Energy Assistance Program (LIHEAP).

LIHEAP is a critically important "safety-net" program that helps the poor pay their utility bills. The premise behind LIHEAP is that the poor should have access to basic utility service. During the 1970s and early 1980s, energy price increases due to geopolitical events and deregulation seriously restricted that access.

Federal funding for LIHEAP peaked at $2.1 billion in fiscal 1985. Since then, Congress has reduced funding for the program by 27 percent, to $1.5 billion. The President proposed to cut LIHEAP even further in fiscal 1989, to $1.2 billion -- an amount 26 percent lower than the fiscal 1980 appropriation for a predecessor program. Because of the steady erosion in federal support for the program, LIHEAP benefits reach just 6.7 million households, fewer than 30 percent of the 23.4 million federally eligible households.

The House and Senate fiscal 1989 budget resolutions earmark $1.6 billion for LIHEAP. Such an amount represents a modest (4 percent) increase over current spending. But it comes on the heels of last year's 16 percent reduction. At an absolute minimum, I urge the Subcommittee to appropriate at least the amount provided for in the budget resolution. I am well aware of the spending constraints we face. But I would urge the Subcommittee to consider restoring even more of last year's cut. For the past three years, LIHEAP has shouldered a disproportionate share of federal budget deficit reduction.

Mr. Chairman, the need for LIHEAP remains unabated. Simply stated, energy costs became a significant -- and in some instances unbearable -- burden for the low income household. Even today, for many impoverished families, the combination of personal income and assistance payments simply is not enough to ensure a minimal standard of living.

Who are these families, and what are their energy costs?

Mr. Chairman, LIHEAP recipients are not "deadbeats". They are unwed mothers. Or the elderly, living on fixed incomes. Many LIHEAP households are headed by or contain handicapped persons. Most contain children. Many households are the working poor. Some are in the grip of seemingly permanent poverty. Others are experiencing a temporary but severe difficulty in meeting their budgets. Regardless of the individual circumstances, when incomes are at or below the poverty level (about $11,000 for a family of four), bills go unpaid. In some instances, families become homeless.

A 1986 study prepared for the National Association for State Community Services Programs (NASCSP) reports that in 1984, 23.4 million households were eligible for energy assistance under Federal income guidelines. The average household had an income of $25,194 that year. The LIHEAP eligible household had an income of $7,239. Under more restrictive State standards, which are permitted by law, the 17.6 million eligible households had a mean income of $6,184 -- less than one-quarter of the national average. These households devote some fifteen percent of their budgets to residential energy costs -- nearly four times the national average.

LIHEAP is vitally important to those families and individuals fortunate enough to receive benefits. For instance, the average recipient household spends all but 6 percent of its income on housing, home energy, and food. In 1984, the LIHEAP household spent:

o 44 percent of tis income ($2,692) on housing;

o 35 percent ($2,192) on food;

o 15 percent ($942) on home energy; leaving only

o 6 percent ($355 for all discretionary expenses.

Imagine having just $30 a month for all discretionary expenses! Just $30 per month for everything else one needs to buy ... from clothing to transportation ... school supplies or eyeglasses or medicine. A LIHEAP benefit of $213 (the national average for that year) boosted discretionary income by 60 percent.

The Northeast-Midwest Institute recently released a report entitled Narrowing the Gap: The Energy Needs of the Poor and Federal Funding. The report states that in 1980, federal energy assistance covered roughly 40 percent of eligible households' heating and cooling costs, estimated at $3.35 billion. For the current fiscal year, LIHEAP benefits will defray just 12.7 percent of those costs, estimated at $9.35 billion.

This abdication of federal responsibility is worse than it appears. Consider that heating and cooling costs amount to just 40 percent of the low income individual or family's total energy costs.

Mr. Chairman, my State -- the Commonwealth of Pennsylvania -- has seen federal funding for LIHEAP shrink from $134 million in fiscal 1986 to $104 million this year. Governor Robert Casey reports that if the President's fiscal 1989 budget proposal were enacted, federal funding would shrink by an additional $23 million. Some 70,000 households could lose their benefits entirely.

So far, the State has been able to hold the line -- 418,000 households continue to receive benefits, which average $234. But further federal funding cuts cannot be absorbed. The reason: Pennsylvania will not be allowed under the Stripper Well court order to appropriate additional state oil overcharge funds for LIHEAP.

In his budget proposal for State fiscal year 1988-89, Governor Casey already requested $30.7 million in state oil overcharge funds for the program. This is the maximum amount allowed under the Stripper Well court order, which put a cap of 75 percent on the amount of funds that can be used each year by a state on all low income programs. Thus, if federal spending is reduced again in fiscal 1989, the Governor will not be able to compensate by requesting a state emergency supplemental appropriation for LIHEAP, as he did this year.

Which brings me, Mr. Chairman, to my last point. Oil overcharge monies cannot be viewed as a panacea to the low income energy assistance problem. Original Congressional intent for the monies was that they be used to supplement, not supplant, a federal commitment to LIHEAP. So much for intent.

But let us ignore that intent for a moment. Surely, Congress has done so. Simply stated, oil overcharge monies are no longer adequate even to supplant federal funding for LIHEAP. States have tapped and just about depleted oil overcharge funds. Eighty percent of those funds have been allocated. What funds remain in Stripper Well accounts must by law be used for a variety of purposes, not just LIHEAP.

The National Consumer Law Center recently surveyed State LIHEAP officials to determine the impact of last year's 16 percent reduction. According to the survey, fourteen states have exhausted their oil overcharge accounts. Thirty-four states plan to reduce benefits and/or the number of households served, close their programs early, or reduce or eliminate LIHEAP transfers to low income weatherization programs.

Congress justified cutting appropriations for LIHEAP all the while ignoring that, even at its peak, LIHEAP benefits reached just one third of the families eligible. And now the oil overcharge monies are nearly spent. We have cut to the bone; now we are cutting through the bone.

Mr. Chairman, allow me to quote from the NASCSP report I mentioned a moment ago. According to the report, "(LIHEAP) assistance is a meaningful supplement to low income household budgets, but these payments, on average, are not high enough to bring the household 'energy burden', or percent of income spent for residential energy, down to its level at the time of the 1978 price explosion." Put another way, too many Americans still are relegated with the choice between heating and eating. It is a choice no American should be forced to make.

STATEMENT OF LEODIS DAVIS, PROFESSOR OF CHEMISTRY, UNIVERSITY OF IOWA

I welcome the opportunity to present testimony on behalf of the budget request for the National Institute of General Medical Sciences (NIGMS). The National Institute of General Medical Sciences is central to the mission of basic research among the National Institutes of Health. Its role in the revolution in health care derived from basic discoveries is unquestionable. The architects of the National Institute of General Medical Sciences foresaw the endless frontier of biology and correctly anticipated the benefits to be derived from supporting basic untargeted, fundamental research. The scientists supported by NIGMS have made basic discoveries which have led to rapid application. The scientific literature is replete with examples of the impact of basic undifferentiated biology on health care. The same is true for the impact of basic biology on the extraordinarily important and new biotechnology industry.

NIGMS has seen the wisdom in supporting the initiation of projects which have started us on great adventures in science and while its mission is not to be involved in specific disease processes in more cases than we can articulate it has started the ball rolling. Many of the advances of the past and of the future result from yoking the advances of many disciplines. Biologists now work at the interfacial areas between biology and other disciplines; therefore, biology is becoming more of an enabling science as opposed to having been more isolated and self-contained in the past. Much of the current efforts of biology are concentrated on understanding one of nature's most extraordinary achievements--the human body. With adequate support the opportunity is at hand to go faster and further than we have in the last few years. We now have a good solid, basic foundation about various factors that influence diseases which should enable us to make some interesting and important advances in health care.

Many of the basic discoveries, by NIGMS supported scientists, of the last thirty years have almost immediately been turned into application and practice. It is critical that support for scientists in the pursuit of non-categorical programs continue. In fact a strong case can be made for increasing the support of basic biomedical research. If we can hope to continue to generate basic advances in biology which represents the mother lode to be drawn from in the development of biotechnological advances as well as therapeutic tools, we must continue to attract some of our best and brightest scientists to this discipline.

We need these scientists to tackle many of the difficult problems of biology we now face. Science depends very heavily upon a foundation of basic knowledge. Many of our current applied advances have been made from ten and twenty year old basic discoveries. It has been easy to transform basic knowledge into application initially since the simplest problems tend to yield to inquiry more rapidly at first and the more difficult one remains unsolved. This is especially true of a maturing science. The revolution in Biology has occurred during the past 20 to 30 years and many of the easier problems have been solved. It is now necessary and fortunately possible to attack many of the more difficult problems. To solve many of these problems requires a greater intensity of investigation. If this level of intensity is to increase then the support by NIGMS of the basic biological scientist must increase. For only by this method can we continue to produce the research which will in the future underpin the scientific solutions to health problems. I would point out that the term biological scientist is used in a very broad sense for the scientists supported under the NIGMS umbrella are drawn from a wide spectrum of fields. The contributions of chemists, physicists, biophysicists, and others is not to be neglected when considerating the advances made in this research area.

Some of the most exciting and significant sciences today is occurring as a result of collaboration between scientists from different disciplines. I have had the opportunity to work at interfaces of biology and chemistry and can personally attest to the impact NIGMS has had on both biology and chemistry and at the interface. I was trained as a biochemist in a chemistry department, first employed in an agricultural college, moved to a biochemistry department in a medical school and most recently served eight years as chairman of a large midwestern chemistry department. Thus, I have been in positions where I could observe first hand the impact of NIGMS function on many different disciplines. Vital to continued productivity in the biological sciences is the support provided by Congress to the training of individual graduate students, postdoctoral students and research physicians. The major mechanism of training each new generation of scientists have been grants awarded ny NIGMS. This institute, as a perusal of its budget will show, provides about one-third of all the funds that NIH provides to both pre-and postdoctoral training.

This area of support is one in which there can be no compromise. It is critical to our national agenda to continue to produce scientists. The number of NIGMS trainees must be maintained. There are many countervailing forces operating to diminish the number. For example, the deleterious situation created by the 1986 Tax Reform Act taxes tuition and scholarships received by graduate students must be reviewed and reversed. This new tax is damaging to the number of biologists who will be trained if it is not reversed. The longer range effect of the taxation will be to reduce the number of scientists in training in this country. It will serve to diminish interest in pursuing careers in biology just at a point in time when demands for them is growing. I believe that nothing must reduce the number of trainees that can be supported by NIGMS.

In conclusion, I wish to thank you for this opportunity to express my views. I am convinced that the Congress will see the wisdom of continuing to fuel the economic growth of biotechnology, to provide the basis of greater and better health care through basic research and to provide the resources for training the next generation of biomedical scientist through its support of the NIGMS budget.

STATEMENT OF THE AMERICAN HEART ASSOCIATION

The American Heart Association (AHA) is dedicated to the reduction of premature death and disability from cardiovascular diseases and stroke. In accomplishing our mission, we work in active partnership with federal research, education and prevention programs whose objectives are similar to ours. One of these is the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). It is a pleasure to provide this Subcommittee with our comments and FY 1989 funding recommendation for the NINCDS. Due to our interest in the use of animals in research, we also have included comments and recommendations about the NIH's Division of Research Resources (DRR). The numbers and dollar figures in our statement for both NINCDS and DRR contain AIDS money.

Cerebrovascular disease (stroke), a cardiovascular disease that affects blood vessels supplying oxygen and nutrients to the brain, is the third largest cause of death in America, after heart attack and cancer. Provisional statistics on mortality indicate that in 1985 alone more than 152,700 Americans died from stroke. In the same year, there were about 1,990,000 people alive who had survived a stroke. About 500,000 Americans suffer stroke each year.

In addition to being a major cause of death, stroke is also a major cause of disability. It is estimated that stroke accounts for half of all the patients hospitalized for acute neurological disease. Also, stroke imposes a tremendous financial burden on society. The AHA estimates that in 1988, the annual cost of stroke-related health care will be $12.9 billion in direct medical expenses and lost productivity resulting from disability. Despite these grim statistics, there is good news. From 1976 to 1986, the death rate from stroke has fallen by 40.2%.

The NINCDS is the Federal Government's focal point for all neurological research including research on the cause, treatment, and prevention of stroke. The Institute's stroke research program consists of a wide range of studies by both individual researchers in facilities across the country and by teams of scientist's in NINCDS-supported stroke and positron emission tomography (PET) research centers. PET produces computer enhanced images of metabolic activity in the brain. Mainly due to the encouragement of the NINCDS, stroke has become a key focus of study at many of our nation's outstanding research institutions.

The NINCDS Stroke Research Program maintains 14 cerebrovascular clinical research centers. As a result of the work in these facilities, stroke is becoming better understood. Also, significant strides have been made in identifying predisposing risk-factors and in discovering new and improved techniques for stroke diagnosis, treatment and prevention. In addition to the center approach, NINCDS-supported researchers conduct multiyear studies on the stroke population to determine long-term damage and treatment effectiveness. Moreover, animal studies still significantly enhance knowledge about stroke.

Stroke prevention is the main goal of stroke research. Research promotes the objectives of stroke prevention, brain function recovery, and an improved quality of life for stroke victims. Significant advances in the stroke field have and will occur from NINCDS funding.

- A large international clinical study showed that a common procedure--extracranial-intracranial (EC-IC) bypass--directing blood past high risk

patient's obstructed brain arteries is no more effective than other medical therapies in preventing stroke.

- **A multicenter clinical trial is in progress to assess the risk and the benefits of another widely-used procedure for the prevention of stroke in asymptomatic patients -- the carotid endarterectomy. This technique which removes the atherosclerotic build-up of plaque from the caroitd artery plus a medical therapy will be compared against the effectiveness of just medical therapy. A second study will examine the efficacy of endarterectomy in symptomatic patients.**
- **A clinical study of a new stroke treatment has revealed the feasibility of treating some stroke patients within 90 minutes from onset of symptoms. Within this time frame, brain cell death maybe stopped.**

The President's FY 1989 budget contains $570.978 million for the NINCDS. Although this budget reflects a 6.8% increase in funding over the FY 1988 appropriation level, it does not sustain adequate growth. This proposed funding level will stifle the NINCDS' ability to continue many of its promising stroke research programs. Specifically, the President's budget will have a significant impact on the Institute's capacity to award competing research project grants. In FY 1987, NINCDS funded 697 such grants and in FY 1988, they will be able to award only 585. Under the President's FY 1989 budget, only 592 could be awarded. Moreover, the percentage of funded NINCDS' study section-approved grants has dropped from 43% in FY 1987 to 33% in FY 1988. The Institute projects that its award rate in FY 1989 will be about 35%.

The number of research centers proposed to be supported by the NINCDS under the President's FY 1989 budget will remain the same as in FY 1988--38--and the level of funding for the center programs will also stay constant. Also, the number of research and development contracts would be reduced by two--66 to 64 with a scant .09% increase in funding. In addition, the research training program would be held at its FY 1987 and FY 1988 trainee number of 653 with a 2% increase in funding.

In FY 1987, the Institute's support for stroke research increased substantially over the FY 1986 level. Since that time, however, its growth has been much smaller. In FY 1988, funding for stroke research increased 6.3% over the FY 1987 level. Under the President's FY 1989 budget, support for stroke research would increase by only 6.8%. AHA is concerned about the support for stroke research.

In the midst of fascinating discoveries in the diagnosis, treatment and prevention of stroke and other neurological diseases, the AHA firmly believes that the Institute must receive sufficient funds to both continue and to accelerate its research momentum. In order for NINCDS to carry out its current programs and to begin additional initiatives, the AHA recommends an appropriation for the NINCDS in FY 1989 of $657.671 million. This level of funding constitutes a 23% increase above the FY 1988 appropriation level for NINCDS.

DIVISION OF RESEARCH RESOURCES

Laboratory Animal Sciences and Primate Research (LASPR) Program

Due to the importance of animals in research, the AHA is interested in the DRR's Laboratory Animal Sciences and Primate Research program (LASPR). The DRR is the NIH's center of focus for helping grantee facilities give proper care and housing for laboratory animals. Created in 1962, the Laboratory Animal Sciences and Primate Research (LASPR) program consists of three parts: Regional Primate Research Centers, Laboratory Animal Sciences Program, and the Biological Models and Materials Resources. LASPR supports the NIH's funded animal and other biological model research projects to make them more effective. In addition, LASPR sponsors research in its seven Regional Primate Research Centers. These centers provide specialized resources and suitable research surroundings for a wide range of basic and applied biomedical studies. This program also supports research and diagnostic laboratories, education of specialists in laboratory animal sciences, development of animal and nonanimal biomedical models, and enhancement of laboratory facilities and additional work which supports various NIH programs. Moreover, LASPR develops and distributes material on the use of biomedical models which may ultimately diminish or replace animals in research. Also, this program helps the NIH Directors' office create guidelines for the humane care and use of animals in research. In this regard, LASPR also acts as a liaison to animal welfare and professional societies.

The President's FY 1989 budget provides $71.972 million for the LASPR program. Although this budget reflects a 8.8% increase in funding over the FY 1988 appropriation, it does not support adequate growth. Under the President's budget, funding for the LASPR's primate research centers would be held constant for non-AIDS activities, laboratory animal sciences would receive a 2.9% decrease, and biological models and materials resources would be increased by 6.9% over its FY 1988 appropriation level. Also, the President's budget holds constant the number of research centers with a 15.8% increase for AIDS activities. Moreover, the animal facilities improvement grant program would be funded at the same level as in FY 1988.

The AHA believes that the President's budget for the LASPR program is inadequate to meet its current and anticipated needs. Its budget should reflect the priority funding that it deserves. Since implementation of the Animal Welfare Act Amendments appears imminent, it is imperative that the LASPR funding accommodate its prospective expanded duties and responsibilities. The animal facilities improvement grant program assists biomedical research facilities comply with both the Animal Welfare Act and the Public Health Service policy on humane care and use of animals. This assistance comes in the form of support for caging sanitation equipment and facility renovation. In order for LASPR to meet its critical needs, AHA recommends that DRR receive a 23% increase over its FY 1988 appropriation level or $452.828 million in FY 1989.

Animals are a crucial component of biomedical research. Reliable findings from this source demand properly trained specialists in laboratory animal medicine, adequate facilities and healthy animals. AHA's recommended funding level will only provide the bare minimum required for the necessary renovation of the majority of our nation's biomedical research institutions' animal facilities and for the control of animal diseases.

Biomedical Research Support Grant (BRSG) Program

Although it is a .24% reduction, the AHA was pleased to note that the President's FY 1989 budget contains funds for the DRR's Biomedical Research Support Grant (BRSG) program. For the past several years the Administration had scheduled it for elimination. Authorized in 1960, the BRSG provides funds for institutions actively involved in biomedical research. These funds support needs not met by other PHS project grants. By allocating these funds to institutions rather than to individual projects, DRR provides the facilities with the flexibility to meet unanticipated needs and emerging opportunities. Our recommended FY 1989 funding level for the DRR, $452.828 million, would allow for the BRSG to meet its current needs.

STATEMENT OF THE NATIONAL COALITION FOR CANCER RESEARCH

Mr. Chairman, members of the Subcommittee, I am Dr. John E. Ultmann, Professor of Medicine and Director of the Cancer Research Center at the University of Chicago. As a volunteer I serve as the Chairman of the National Coalition for Cancer Research. With your permission, I ask that my full statement be included in the record and I will briefly highlight my testimony.

The National Coalition for Cancer Research is made up of nearly every cancer research, cancer care and lay group in this country representing over 65,000 cancer researchers, nurses and physicians, 325 cancer hospitals, centers and clinics, and 57 cancer research centers. On behalf of these individuals I thank you for the opportunity to appear before the Subcommittee today to discuss funding for our National Cancer Program.

Before I focus on the needs of our research program, please allow me to thank this Subcommittee for your support of the National Cancer Institute and the National Cancer Program in years past. I am keenly aware of the budget constraints that you face this year and recognize the hard choices that you have made in the past to invest so wisely in medical research programs. I applaud these choices, and I am pleased that you have advocated so strongly to invest in the health of tomorrow's citizens.

I join the ranks of everyone else who has sat before you and requested increased funding. I welcome the opportunity to build the case for our National Cancer Program.

Tremendous progress has been made since the founding of the National Cancer Institute (NCI) over 50 years ago. I refer you to our brochure which I have brought with me and request that it also become part of the record. As you will see on page 7, there is progress in every area. The commitment to basic research programs in cancer over the past 17 years has brought us much closer to understanding how the cancer cell works and the future direction of our research initiatives.

At the present time, we are standing in the midst of a biomedical revolution in cancer research. Our nation's investment in cancer research has created a strong and solid foundation to reach for treatments, including cures, and prevention, including vaccines. Cancer research has enabled us to state that today cancer is a solvable problem -- something that we now understand and will be able to control in the not too distant future -- as long as the necessary resources to our National Cancer Program are provided.

For 1989, the NCI's statutorily required By-Pass Budget, endorsed by the National Cancer Advisory Board, is requesting a total of $2,080,000,000. This figure includes funding for Cancer Research Programs of $1,968,000,000 and Cancer Control Programs of $111,371,000 which support a major part of NCI studies aimed at preventing cancer. The total is an increase of $611,744,000 over the FY 1989 President's Budget Request of $1,468,744,000.

While this figure may be overwhelming to all of us, the cost of cancer each year is over $70 billion. More people die from cancer each year than in all of our wars combined.

Attached to my remarks is a chart from the NCI's Report to the President's Cancer Panel on the reauthorization of the National Cancer Act which reflects the overall growth of the National Cancer Institute as compared to the other NIH components since 1979. This chart shows that NCI increases a percentage basis have been consistently lower that other Institutes at the NIH.

The By-Pass Budget figures represent sums which the scientific community and the National Cancer Advisory Board believe are necessary to confront cancer and expand our capablities against this dread disease. This sum would allow NCI to:

* Fund 50% of the approved and competing research project grants at the recommended levels compared to 39% for fiscal 1987.

* Increase the number of Cancer Centers by 10 as a means of broadening their geographic distribution.

* Support cancer prevention and control programs at an increase of approximately 65% above the current FY 88 prevention and control budget of $69 million.

* Improve access to promising therapies by doubling the number of persons enrolled in clinical trials from 25,000 in 1987 to 50,000 by 1992.

* Support 1,600 trainees, as compared to 1,475 in FY 1987 through the National Research Service Awards.

* Provide $10 million to meet the extramural community's needs for scientific instrumentation.

* Provide funds for a special initiative to upgrade and expand biomedical research computing capabilities.

This level of funding is vital if we are to achieve the goal established by the National Cancer Institute for the year 2000 --reducing the death rate in this country from cancer by 50%. It is important to point out that this goal must be considered in the context of the "graying of America." The U.S. has the world's third largest elderly population and the largest number of citizens over the age of 85. We have long recognized that as an individual ages, the likelihood of developing cancer increases. Thus, this goal becomes even more astonishing when you realize that the incidence of cancer is, in fact, expected to increase.

CANCER RESEARCH INFRASTRUCTURE

There is a tremendous need to modernize our basic biomedical laboratory and clinical research facilities in order that we can continue to be in the forefront of international biomedical research. This is true not only for cancer research but for the entire biomedical research community. While it is essential to provide increasing opportunities to pursue research, it is equally important to recognize and provide the infrastructure and resources necessary to continue that research.

The last NIH-wide construction program was in 1968. As you know the Congress had the foresight to provide the National Cancer Institute with the authority to award construction grants in 1974 when the National Cancer Act was reauthorized. This program has been a life-saver for the cancer and biomedical research community, although I must acknowledge that the resources available to this program have been less than adequate over the last several years. It is a severe problem that none were provided in FY 1988. The President's Budget Request for 1989 again provides no funds for construction.

The White House Panel on the Health of U.S. Colleges and Universities, also known as the Packard Commission, reported in 1986 that the infrastructure in research and academic institutions needs updating. This White House Report estimates that it would cost about $10 billion over the next 10 years to improve the facilities, construction and infrastructure problems in academic institutions.

Decline in federal support for academic research facilities has dropped 85%, when adjusted for inflation, during the past two decades. And yet, increased health and safety requirements, increased need for environmental protection and new regulations for animal research facilities necessitate improved research facilities.

A recent survey conducted by the National Science Foundation revealed the following.

* Current construction and renovation is being concentrated on the top 50 institutions
* Most of the current construction and renovation is financed by the State and private sources -- almost one-third by tax-exempt bonds. The Federal share is about 10 percent, most of which is for special projects.
* Most researchers and administrators believe lack of facilities limits their ability to conduct research projects.

The Coalition supports the NCI's By-Pass Budget request for new resources to maximize our investment for construction and renovation projects. This request was based on a study of construction needs sponsored by Dr. Armand Hammer, Chairman of the President's Cancer Panel and the American Cancer Society.

The future holds great promise. Scientific discoveries are coming at an unprecedented rate, and the NCI has built the network necessary to translate and apply them. By our working together and by our continued efforts in both the public and private sectors, we will sooner --rather than later -- fulfill the mission of the National Cancer Program to conquer cancer. Your past support has brought us closer to obtaining this goal -- your continued support is necessary for us to achieve it.

Mr. Chairman, I am aware of your responsibility to this nation to act fiscally responsible. I, as a physician, researcher and parent, also have a

responsibility -- to reduce the incidence of cancer and its death rate for all Americans. Mr. Chairman, I hope to soon see the day when the priorities of this nation allow you to help me, and my colleagues, to meet our responsibility with the full resources necessary.

This concludes my formal remarks. I will be happy to answer any questions that you may have.

STATEMENT OF THE ASSOCIATION OF PROFESSORS OF MEDICINE

Mr. Chairman, I am President of the Association of Professors of Medicine and Chairman of the Department of Medicine of the Boston University School of Medicine. The Association of Professors of Medicine represents the departments of medicine of the 127 medical schools of the country. Of the 104,000 internists in the U.S.A. approximately 11,000 serve as faculty in Departments of Internal Medicine. In addition, there are 18,000 resident physicians training in Internal Medicine Departments. As teachers and clinicians, we experience daily the benefits of improved medical care - fewer premature deaths, reduced pain, faster healing, shortened hospital stays, extended and more productive lives -- which has become the rightful expectation of Americans of our generation.

My purpose is to ask for the strengthening of two programs which have been essential to the medical progress we have known: assistance to departments of medicine and their students under Title VII of the Health Professions Manpower Act; and support for basic medical research carried out under the National Institutes of Health.

As you know, the Senate Labor and Human Resources Committee has under consideration S. 2229, the Health Professions Reauthorization Act. The funding provided since the 1970's for the training of primary care specialists under this program -- including general internal medicine specialists and pediatricians -- has been an outstanding investment in improving the access of all Americans to quality health care.

We have heard, in recent years, about the impending "physician surplus." Overall, these projections were probably exaggerated. In the case of internal medicine, they were off the mark to begin with and have been rendered obsolete by changes in medical practice and trends in medical school and post-medical school choices of specialties. We are encountering the long-expected effects of an aging population, which again puts greater demands on the primary care physician; we are encountering new diseases, such as AIDS, with new demands of primary care physicians; we are learning that the increased percentage of women in medical practice translates into fewer work hours and fewer work years per physician, as women physicians understandably put some of their time and energy into their families.

Neal Vanselow, M.D., Chairman of the Council on Graduate Medical Education, has recently reported to the Senate the conclusions of that organization that "there appears to be an impending undersupply of physicians in general internal medicine" and that "existing Title VII primary care programs should be continued." These recommendations recognize that it is the general internists who provide the largest portion of adult non-surgical medical care in this country.

In the face of these clear needs for the continued development of primary care training programs, the recommendations of the Administration virtually to eliminate funds for general internal medicine and pediatrics under Title VII should be rejected. These funds are used to create and maintain primary care programs. It is important to fund both the programs that train doctors to practice primary care medicine and the programs that develop general medical faculty for the nation's medical schools. This committee has reviewed and wisely rejected similar recommendations in the past to zero out these programs in favor of a small but amorphous "block grant." Your wisdom in supporting medical education in these areas has been recognized by the new conclusions now emerging from COGME and other respected sources.

The Title VII reauthorization bill would provide $22 million for funding in general internal medicine and pediatrics for the next three years, a small increase from the present level. We strongly urge this subcommittee to recommend an appropriation at this level.

Our second concern is with the level of support for basic biomedical research. We appreciate and salute the strong support that the members of this committee have given to NIH in the past. The Congressional appropriation for NIH research last year was 7.8 percent above the appropriation for the previous year and 20 percent above the Administration's request. This was sufficient to maintain the pace of NIH research; but unfortunately was insufficient to increase the effort. Significantly, less than one third of grant proposals approved by NIH peer review as meritorious and worthy of funding could be supported and many of those sustained substantial budget reductions.

This year, the Administration request for NIH biomedical research funding shows a greater appreciation of the value of medical research and of the importance of NIH leadership. The $6,535,000,000 request (excluding AIDS research) represents an increase of 5.4 percent over 1988. (Special funding for AIDS research raises the total request to $7.1 billion).

In this era of budgetary restraint, are we here to ask for a further increase in funding? Yes, that is the recommendation I bring to you and without apology. The record of the NIH speaks for itself. A few examples:

-- The development of tissue plasminogen activator (TPA) and other new cardiac drugs which, can prevent permanent injury during a heart attack. Previously, care was limited to measures which minimized complications but could not reduce the injury to the heart. Now there is the opportunity to prevent serious damage and then treat the patient to reduce the likelihood of recurrence. This new technique may save many thousands of lives every year and enhance the quality of life for survivors and reduce the frequency and hence the costs of subsequent hospitalization to both Medicare and private insurance carriers.

-- Another example is the possible drug management of arthritis. Rheumatic disease afflicts nearly 37 million Americans and costs all of us about $25 billion a year. With drug therapy developed as the result of NIH research, we can now largely prevent the chemical damage to joints caused by gout and reduce damage in other forms of arthritis. Modern drug treatment greatly decreases pain and disability in Americans afflicted with these potentially crippling illnesses.

-- Basic research in cholesterol metabolism has led to a truly effective new medication which will reduce cholesterol levels in virtually everyone. For those with hypercholesterolemia, this will lead to a reduction in heart and vascular disease.

-- Basic research in virology, molecular biology, and immunology has permitted new vaccines to be developed, such as the very successful hepatitis B vaccine. Other antivirus vaccines are in development, offering the best long-term hope for control of such diseases as Herpes, AIDS, and forms of cancer caused by viruses.

These examples merely illustrate some applications of basic research to direct care of patients. Other witnesses will have many more examples of opportunities to be seized, in biotechnology, immunology, cell biology, molecular biology, pharmacology and other fields of basic research; and of the application of this research in the prevention and treatment of diseases as recent as AIDS and as ancient as cancer.

Unfortunately, the Administration request will not maintain the pace of current investigation because research has become more costly. A number of factors contribute to the increase in research costs. New technologies require highly sophisticated equipment, the provision of advanced laboratories, and highly skilled laboratory technicians. In addition biomedical research employs new and expensive precautions which are necessary with the use of human volunteers, with the care of research animals, and with the viruses and infectious agents used in research laboratories. There is no avoiding these new costs of research. Therefore, real growth and acceleration in response to new ideas requires better support than has been provided.

One critical example: under the Administration proposal, the number of new and competing non-renewal grants - a basic measure of the ability of NIH to support new researchers in new biomedical research areas - will actually decline by almost 300. Moreover, the budgets of ongoing research grants will be cut by 8-15% from their previously approved levels. Since a large proportion of research funds is used to pay personnel, this will mean layoffs of highly trained researchers and disruption of scientific programs. We should not permit this to happen.

The direct economic benefits of medical research should also be noted. Quite apart from the economic and social benefits of successful medical treatment, biotechnology also means economic growth and opportunity. The Department of Commerce forecasts a positive balance of trade in medical equipment of approximately one billion dollars next year. Some estimates are that biotechnology could be the fastest growing of all export opportunities. The Japanese have had the wisdom to target biomedical technology for increased research and financial support, just as they previously targeted steel production and semi-conductors. They know how to identify opportunity and respond. I hope we will do as well.

We therefore support the recommendation of the Ad Hoc Group for Medical Research Funding for an NIH appropriation of $8,221,000,000 including AIDS research. The proposed level of research support is less than 2 percent of the cost of health care in the U.S. This recommendation has been carefully structured to provide for a small increase rather than a fall in the percentage of qualified research applications which NIH will be able to fund and to eliminate cutbacks in important ongoing research. The benefits of greater support of research are clear. Death and suffering of American citizens will decrease. The cost of medical care will fall. Our national leadership in medical science and technology will be preserved.

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